# **EXECUTIVE SUMMARY**

#### STUDY TWO:

#### **IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE**

# **OBJECTIVES**

The goal of this study was to describe common patterns of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs. The analyses capitalized on the unique longitudinal qualities of the data from the Alzheimer's Disease Demonstration Grant to States project (ADDGS) and the diversity of the study sample.

#### **METHODS**

Data were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. Information about demographic and functional status of elders and caregivers was gathered as part of the client intake process. Data pertaining to clients' use of services were taken from providers' records. Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing respite services in day care and in-home settings. Multivariate and multi-level data analysis techniques were used to analyze the longitudinal data and create profiles of respite use.

#### **FINDINGS**

Almost one third of the demonstration clients used respite services for only one or two months and the mean length of use was ten months. White clients were most likely to be brief users. Black/African-Americans were least likely to be brief term users of day care and Hispanic/Latino clients are least likely to be brief users of in-home. This pattern may reflect the success of the ADDGS demonstration with promoting programs that effectively serve traditionally under-served populations.

The decision by clients to continue or discontinue use of services was related to characteristics of the service providers. The positive relationship observed between brief user status and problem

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behaviors likely reflects the limited capacity of day care providers to care for persons with problem behaviors. As long as elders were able to function in a day care setting, they continued to use that service. When elder impairment became too high, families were likely to seek in-home services. Day care was most often used as a support system when caregivers needed to be away from home or when caregivers had other obligations that required their attention. When the impairment level of the elder increased to higher levels, adult children who could not leave a parent home alone were more likely to cease caregiving.

Brief users of in-home respite appeared to constitute a sub-population of caregivers with unmet needs who had a greater need for professional health and household assistance. Consequently they tended to discontinue use of programs that were staffed by volunteers that did not provide health related services and that often did not have set fee structures.

To fully capture variations in patterns of respite use, it was important to examine multiple measures of use including duration, continuity, and intensity of respite use. For extended users of respite, mean duration of service use was 16.2 months for day care clients and 14.9 months for in-home use. Day care clients used twice as many hours of service each month (50.3 versus 24.6) and almost three times (817 versus 283) as many hours of care over their full duration of service use.

# Client characteristics were the primary predictors of the duration, continuity, and intensity of service used.

- Persons with high levels of IADL impairment used day care services for a shorter duration, but with greater intensity. Among users of in-home respite, higher levels of ADL impairment and problem behaviors were associated with more intense use of services. For users of both types of services, the number of hours of service used each month increased with duration.
- Clients assisted by a spouse were more frequent users of in-home respite programs, but they used significantly fewer hours of respite each month than did their peers who were cared for by adult children or other more distant relatives. Elders with male caregivers used more respite services.
- Different ethnic groups had distinct trajectories of day care use over time. Compared to Whites, Blacks/African-Americans tended to use smaller quantities of service over a more extended period of time. Hispanic/Latino elders used high quantities of service for shorter periods. Notably, the two

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groups of minorities did not differ in the average total number of hours of day care use.

Middle-income elders were the highest users of in-home services. For this client group in-home respite was probably the most economical solution for long term care because of limited discretionary money and ineligibility for Medicaid as a source of payment for nursing home care.

Two provider characteristics influenced the intensity of respite service use over time. Families who sought respite from programs that offered a health care component used services more intensely. This trend likely reflected the higher levels of elder need. In general, clients used services more intensely when the maximum limit for services was higher, although they did not necessarily use more services over the duration of their use. This pattern suggests that arbitrary caps on services may impede effective distribution of resources among clients with different levels of need.

#### PRACTICE IMPLICATIONS

Accurate cost estimates for respite services cannot be made without clear knowledge of client variations in the duration, continuity, and intensity of respite use. When providers plan and budget for respite services it is useful for them to consider the characteristics of their client population, which are directly linked to variations in patterns of use.

It is important to offer multiple forms of respite to meet the needs of different segments of the client population and to provide support for families, as needs change over time.

When designing respite services, attention should be given to both the level of care provided and the type of respite services offered.

Limitations placed by providers on the number of hours of service available to clients are likely to create significant barriers to service use if they are not appropriately tailored to match client characteristics.

# STUDY TWO:

# IDENTIFICATION OF PROFILES OF RESPITE SERVICE USE

#### INTRODUCTION

#### <u>Purpose</u>

The goal of this study is to provide initial answers to questions about patterns of respite use by describing the common long term profiles of use among a diverse sample of families. Despite the limited availability of empirical evidence supporting the benefits of respite, practitioners have gone forward with the development and implementation of respite programs. However, currently little practical information available to help providers plan and execute programs in an efficient manner. The simple fact is that very little is known about how caregivers actually use respite in their everyday lives.

Thus, there is a need for basic information about patterns of respite use. In a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity? Are there differences in use patterns associated with the relationship of the caregiver to the elder, (i.e. spouse versus adult child)? Are patterns of service use associated with disability level of the elder, geographic regions, or cultural backgrounds of families? How do patterns of use differ for different types of respite programs (day care or inhome)? How do constraints in respite availability alter patterns of use? Answers to these questions would allow policy makers and service providers to make informed decisions about respite funding and program development.

# Factors Likely to Influence Respite Utilization

The diversity of caregivers and their caregiving contexts is now well established by a large body of research conducted over the past two decades. This current study was undertaken with the expectation that diversity among caregivers and their contexts would likely be reflected in patterns of respite use. Specifically, three sets of variables were investigated as plausible factors affecting patterns of service use: cultural differences, differing caregiving careers, and service availability.

#### **Cultural Differences**

An abundance of studies have documented great variation in the quantity, intensity, and continuity of care that is provided by family members. Patterns of family care have been linked to the ethnic background of the family, the geographic location of the family, and the familial relationship of the caregiver to the elder (i.e. spouse, child, or other family member). (See Study One for a further discussion.) Although the level or type of impairment of the elder may determine the need for care decisions, the type of care that is provided, the specific individual provides the care, and the manner in which it is provided are largely influenced by characteristics of the caregiver. It was therefore reasonable to assume that patterns of respite use are also linked to these differences in caregiving contexts.

# **Caregiving Careers**

Another important aspect of informal caregiving is its dynamic nature. Caregiving has been likened to a career of variable length (Montgomery and Kosloski, 2000; Pearlin et al., 1990; Zarit, 1993). As such, the caregiving history for each person has (1) a beginning, (2) some definable temporal extension or duration, and (3) an end or resolution (e.g., recovery, death or nursing home placement). Although the caregiving process or career can be described in temporal units, time is unlikely to be an adequate descriptor. Hence knowing, for example, that a caregiving relationship has existed for 12 months does not provide much useful information about the specific needs of a given family, their prospects for continued caregiving, nor their use of respite services. There is a great deal of individual variation in the trajectory of caregiving careers. This variation has been shown to be related to a number of demographic and attitudinal characteristics of the caregiver and the care receiver (See Montgomery and Kosloski, 2000; Kosloski and Montgomery, 1993b; Zarit, 1993). Changes in patterns of care have also been linked with changes in elder functioning (Peek et al., 1997), caregiver functioning, and the availability of support from both informal (Gill et al., 1998; Worcester and Hedrick, 1997) and formal sources (Bass et al., 1996). The dynamic process of caregiving is also likely to affect respite use over time.

# Service Availability

Obviously, respite services must be available for families to use them. Yet, like respite use, availability is not a dichotomous variable. Availability of services may be described in terms of quantity, type of service, and hours of operation. Both formal and informal criteria are used to make services available to some caregivers and not to others. Individual and family

characteristics not only influence caregivers' choices, they also influence providers' decisions about service availability. Concerned with maximizing their resources, providers make choices about hours and times of operation and they create eligibility rules for rationing and/or distributing services. Guidelines for rationing scarce resources can be formal rules such as caps or limitations on the number of hours or dollars available to different clients. Rationing can also occur in informal ways through waivers or exceptions to established caps. Such informal criteria often reflect a case manager's subjective perception of family need. Hence, program characteristics such as hours of operation, service caps, flexibility of rules, and the discretionary decision-making of case managers can also affect patterns of client use.

#### Potential Contributions of study for Policy and Practice

The findings from this study are particularly useful because they stem from analyses of longitudinal data, which provide unique insights into long term patterns of respite use. For the most part, previous studies of respite services have been limited in scope and sample size. In the past, the limited nature of resources for large, longitudinal demonstration studies has prevented a thorough analysis of diverse patterns of respite use. However, in 1991 when Congress passed the legislation for the Alzheimer's Disease Demonstration Grants to States (ADDGS), it mandated an evaluation of the program. Although initially the ADDGS project funded for only three years, the evaluation was designed to take advantage of longitudinal data should they become available. Fortunately, the three-year demonstration project has now completed its ninth year and an extensive data set has been developed to address several important questions about caregivers' use of respite over time. As part of the mandated evaluation, longitudinal data were collected about client families and their use of support services.

The findings from these analyses will potentially benefit several groups. First, providers responsible for developing respite programs can use the findings to plan more efficiently and tailor programs to the characteristics of persons in their catchment area who are most likely to use services. Providers who already have respite programs in operation may use the information to modify service delivery of their programs and increase the benefits to users. With detailed information about current and preferred patterns of respite use for different segments of the elderly population, providers will also be able to more accurately assess the level of

community need and determine likely costs for the delivery of respite services more appropriately. Additionally, it will help providers to distribute their resources more effectively by understanding the diverse ways in which different caregivers, with different needs, use services. Thus, the arbitrary limits (service caps) providers sometimes apply may give way to more appropriate targeting and dosing of services.

Second, knowledge of the patterns of respite use identified by this analysis will be useful to policy makers and planners who must estimate the long term costs of service delivery. Very little is known about the long term use of respite by families in real community settings. The patterns observed in this study, which focused on a multitude of programs operating in a variety of communities, are likely to vary dramatically from the artificial conditions of most evaluation studies.

Third, the findings from this study will assist researchers who are attempting to answer the ultimate question of cost effectiveness. Quite frankly, there is little consistency in the definition of "respite use" in evaluation studies. By observing how respite is actually implemented and used across a wide range of programs, it may be possible to develop definitions of "respite use" that are applicable to real-life settings that can be employed in future studies.

#### STUDY DESIGN

#### **Study Questions**

Four basic questions concerning patterns of respite use among a diverse sample of families caring for an elder with dementia have been addressed:

- 1. What is the duration of respite use?
- 2. How much respite is used?
- 3. How consistently or continuously do families use respite?
- 4. Do patterns of service use change over time?

In addition to addressing the four basic questions, the analysis also focused on three questions pertaining to differences in patterns of respite use that are likely to be associated with

characteristics of families and/or providers:

- 5. Do patterns of respite use differ by type of respite service (e.g. in-home or day care)?
- 6. To what extent are patterns of respite use associated with characteristics of the caregiver or elder?
- 7. To what extent are patterns of respite use associated with characteristics of service providers?

# **Study Population**

Data for this study were gathered from 4,369 client families and 122 service providers who participated in the ADDGS demonstration in the District of Columbia, Florida, Maine, Michigan, North Carolina, South Carolina, and Washington. These seven states were selected for inclusion in this study because the data for these states were deemed to be most reliable and best represent the cultural diversity of the demonstration. The study population includes all client families from the seven states who used in-home respite or day care services provided through the ADDGS demonstration between September 1992 and December 1998. Although a broad range of support services (e.g., case management, transportation, education, support groups, and legal assistance) and respite services were provided through the ADDGS, only families utilizing in-home respite and day care services were included in the analyses for this study. Data from families using institutional and residential respite were not included because the number of families (less than 2%) using these services was too small for reliable analyses. Families qualified for participation in the demonstration if the elder showed signs of dementia; a formal diagnosis of Alzheimer's disease was not required. The 122 agencies included in the analyses were identified as the providers of services used by the 4,369 clients included in the study.

# **Client Families**

#### **Data Collection**

Client data for this analysis were obtained from three sources. Information about demographic characteristics of the elders and caregivers as well as the functional status of elders was gathered as part of the intake process at the time of client enrollment (See Appendix 2A). Data

pertaining to clients' use of services were taken from providers' records (See Appendix 2B). Finally, to obtain information about the current care status of each client, a special query was sent to providers. Providers were asked to identify those clients who were continuing to use project services and those clients who had stopped using services. If a client no longer used the project's respite service, providers indicated whether the client had moved out of the service area, moved to a care facility, died, or continued to live within the service catchment area. When possible, providers also reported the date of death or transition to a different care source (see Appendix 2C).

#### Client Characteristics

As shown in Table 2.1, the largest percentage of respondents was from the state of Michigan, representing 32.7% of the sample. Families from Washington comprised the smallest segment accounting for only 5.7% of the study group. Each of the remaining five states contributed between 8.6% and 16.6% of the study population. The demonstration project was particularly

**TABLE 2.1. DISTRIBUTION OF SAMPLE** 

	Number of Families	
	4369	%
State		
Washington D.C.	407	9.3%
Florida	725	16.6%
Maine	375	8.6%
Michigan	1429	32.7%
North Carolina	469	10.7%
South Carolina	713	16.3%
Washington	251	5.7%
Service Type		
Day Care	1679	38.4%
In-Home	2176	49.8%
Both services	514	11.8%
Race		
White	2483	56.8%
Black/African-American	1378	31.5%
Hispanic/Latino	335	7.7%
Asian/Pacific Islander	108	2.5%
Native American/Alaskan	14	0.3%
Unknown	42	1.0%
Geographic Location		
Urban	1760	40.3%
Rural	2331	53.4%
Unknown	278	6.4%

targeted to minority populations and rural communities. Consequently the study sample includes larger numbers of minorities and rural elders than is usual for caregiver studies. Across all sites, users of in-home respite accounted for nearly fifty percent of the sample, while day care clients comprised 38.4%. In addition to families that used one type of respite, some families accessed both types of respite services. These dual users made up 11.8% of the study sample.

Just under 57% of persons in the primary sample were White. Black/African-Americans accounted for 31.5% with Hispanic/Latinos making up slightly fewer than 8%. Individuals designated as Asian/Pacific Islander, Native American/Alaskan and unknown ethnicities comprised the remaining 4% of the sample.

More than one-half (53.4%) of all participants reported living in geographic areas classified as sparsely populated or rural. Urban dwellers (i.e., those residing in cities with populations of more than 50,000) comprised 40.3% of the sample. Data pertaining to geographic residence were not available for 6.3% of the sample.

The records of the 4369 families were used to create two data sets for separate analyses of utilization of in-home respite services and day care services. A total of 2193 cases (1679+514) were included in the day care sample and 2690 cases (2176+514) were included in the in-home sample. There were 514 (12%) families that utilized both in-home respite and day care and thus, were added to each service sub-sample.

# Service Providers

A total of 122 agencies from the seven sites were identified from project records as ADDGS service providers for clients included in the longitudinal sample. At the time of data collection (Fall 1999), 104 agencies were still providing respite services to demonstration clients. Eighteen agencies were either closed or no longer participating in the ADDGS but programmatic information was obtained from former directors. Thus, detailed programmatic information was obtained from 112 direct service providers. The remaining 10 agencies were providers that

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operated as umbrella organizations, or portals, that directed care for clients through a variety of subcontracting agencies. Portal agencies directly provided case management activities but contracted with other agencies for respite services. As a consequence, uniform information regarding programmatic policies of day care and in-home providers was unattainable for clients served through these 10 portal agencies. Additionally, thirty-five of the 112 direct care providers offered more than one type of respite (i.e., group day and in-home). In these cases, information was gathered on each program component.

#### **Collection of Provider Data**

Telephone interviews were conducted with key staff members to obtain programmatic information from the 122 agencies providing demonstration day care and in-home services. A structured data collection instrument (see Appendix 2D) was developed to gather relevant information. A copy of the data collection instrument was sent by letter or facsimile to the state coordinator of the ADDGS sites as well as to the agency service providers. Respondents were either state coordinators or direct care providers of the services. In some cases, the respondents completed the form and mailed it to the study team. Follow-up telephone calls were then made to all respondents to clarify any information that was not completely reported. For those who did not return the form, telephone interviews were completed with each agency representative to gather the needed information.

Data were collected about the following program characteristics for both day care and in-home respite services: service caps (maximum hours available), service availability, changes in caps and availability over the period of the demonstration, provider amenability to waiving caps, fee structure, type of staffing (paid/volunteer), level of care, and location. Additionally, for in-home programs, information was gathered about the availability of services during evening hours and on weekends. For day care programs, information was also obtained about hours, days of operation, and the availability of transportation.

#### **Provider Characteristics**

Table 2.2 reports provider characteristics by type of service. A total of 76 day care and 50 inhome respite providers are included in the sample. The sample only includes programs that provided direct care to clients in the sample. Programs that functioned as gateways or point of entries only, and did not provide direct services, were not included in the sample.

TABLE 2.2 PROVIDER CHARACTERISTICS BY SERVICE TYPE

	Day Care			e Respite
	N	<b>76</b> %	N 5	5 <b>0</b> %
State of Location				
Washington D.C.	2	2.6%	1	2.0%
Florida	10	13.2%	6	12.0%
Maine	5	6.6%	5	10.0%
Michigan	17	22.4%	12	24.0%
North Carolina	16	21.1%	12	24.0%
South Carolina	19	25.0%	9	18.0%
Washington	7	9.2%	5	10.0%
Annual Service Cap (hours)	mea	n = 792	mean	= 406
Change in Service Cap				
Decreased Cap	10	13.2%	10	20.0%
Increased Cap	23	30.3%	9	18.0%
No Change	43	56.6%	31	62.0%
Service Availability (hours monthly)	mear	า = 91.6		
Daytime Only			32	64.0%
Anytime			18	36.0%
Change in Availability				
Decreased Availability	5	6.6%	4	8.0%
Increased Availability	27	35.5%	7	14.0%
No Change	44	57.9%	39	78.0%
Service Cap May be Waived				
Yes	14	18.4%	19	38.0%
No	62	57.6%	31	62.0%
Fee Structure				
Percentage Copay	4	5.3%	5	10.0%
Set Fee Structure	10	13.2%	4	8.0%
Sliding Scale	48	63.2%	23	46.0%
Voluntary Contribution	14	18.4%	18	36.0%
Staffing				
All Paid	25	32.9%	31	62.0%
All Volunteer	0	0.0%	0	0.0%
Paid and Volunteer	51	67.1%	18	36.0%
Unknown	0	0.0%	1	2.0%
Level of Care				
Socialization/Companionship Only	40	52.6%	5	10.0%
Health/Personal Care	36	47.4%	42	84.0%
Unknown	0	0.0%	3	6.0%
Transportation Provided				
Yes	31	40.8%		
No	45	59.2%		
Type of Day Care				
Adult Day Care	39	51.3%		
Group Respite	30	39.5%		
•				
Both	7	9.2%		

The majority of providers for both day care and in-home respite were located in Michigan, North Carolina, and South Carolina. Providers in these three states comprised approximately 20% of providers of each type of service. Only 2% of the day care providers and in-home providers were located in the District of Columbia. Providers in Florida, Washington, and Maine accounted for about 30% of the sample with between 7% and 13% of the providers of both types of service located in each of these states. It is important to note that distribution of the provider sample does not correspond to the distribution of clients across the various states because providers varied significantly in the number of clients they serve.

The annual service cap of a provider reflects the maximum number of service hours allocated to clients per year. The average annual service cap for day care agencies of 792 hours was two times greater than the average cap of 406 hours for in-home agencies. This disparity between service caps is readily explained. Since day care is typically provided in 4 to 6 hour allotments and in-home care is generally offered in 2 to 3 hour allotments, the number of instances or days of use is more comparable than is the number of hours.

Over the course of the ADDGS, service caps changed for approximately 40% of both day care and in-home agencies. Among day care programs, increased caps (30.3%) were more common than decreased caps (13.2%). However, for in-home respite, the percentage of increased caps to decreased caps was relatively the same (20.8% to 18%).

Service availability was evaluated differently for the two types of respite services due to structural differences in their delivery. In general, day care agencies maintained set hours of operation, yet the number of days and the length of time available varied dramatically across sites. As a result, availability for day care is represented by the mean number of hours. Inhome respite providers typically operate on an appointment basis. Consequently, availability is more clearly represented by times of the day that clients have discretion to use service (i.e., daytime only or anytime). On average, day care agencies were open 92 hours per month. Based on a six-hour day, day care programs were available approximately 15 days a month. One-third (36%) of the in-home programs made services available at any time, while the remainder provided services only during daytime hours. The majority of agencies did not change times of service availability over the duration of the demonstration. However, when

changes did occur, availability was typically increased. The majority of respite programs did not offer waivers on service caps. Of those that did, in-home agencies were more likely to offer waivers (38%) than were day care agencies (18.4%).

Providers in the ADDGS employed four fee structures including: co-payment requirements, set fees, sliding fee scales, and voluntary contributions. The most common fee structure for both types of service was a sliding fee scale followed by voluntary contributions. Almost half (46%) of the in-home programs and almost two thirds (63.2%) of the day care programs used a sliding fee scale. The fee structure for 36% of the in-home providers and 18.4% of the day care programs was voluntary contributions. Clients were less likely to encounter requirements for copayment or set fees. Only four (5.3%) day care providers and five (10%) in-home providers used co-pay structures. Ten (13.2%) day care providers and four (8%) in-home providers had a set fee structure.

The most common types of fee structures, sliding fee scales and voluntary contributions, are also the least distinctive in practice. Agencies that assess fees according to a sliding fee scale generally use income guidelines as a basis for these charges. Similarly, agencies employing voluntary contributions often suggest an appropriate contribution according to family income or leave the amount of the contribution to the discretion of the family. A few agency directors expressed the sentiment that when an income guideline was used to suggest voluntary contributions, most client families were strongly encouraged to make the recommended contribution. There were also a number of agencies that provided services without any charge to the demonstration clients. Across sites, providers reported considerable flexibility in assisting clients with service costs. The majority of providers reported that clients were not refused services for an inability to pay and that occasionally other funding sources were available for clients who could not make the expected minimum payment.

Respite agencies staffed their respite programs with paid workers or a combination of paid workers and volunteers. No providers reported using only volunteer staff. Volunteers were much more likely to be working for day care centers than for in-home agencies. Approximately two-thirds (67.1%) of the day care agencies in this sample were staffed by a combination of paid and volunteer workers. Conversely, only one-third (36%) of in-home agencies employed both

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paid and volunteer staff.

Respite agencies in this sample also offered differing levels of physical care. Just over half (52.6%) of the day care programs limited care to socialization or companionship. The remaining 36 (47.4%) programs provided health related services. In contrast, the large majority (84%) of in-home programs offered health care and personal care services. Only five (10%) of the in-home providers limited their services to socialization or companionship.

Approximately 40% of the day care providers in the sample provided transportation services to their clients. Just over half of the day care programs offered full-day (six or more hours) services three or more days per week. These programs were categorized as *adult day care programs*. Thirty (39.5%) of the day care respite programs were categorized *as group day respite programs* because they provided services that were limited in scope to three to four hours of services one or two days per week. Seven (9.2%) of the providers offered both types of day care programs.

#### Strategy for Data Analysis

Two sets of analyses were conducted to fully describe the patterns of respite use by clients. The first set of analyses focused on clients who used services for only a brief period. These analyses included all clients who limited their use of respite services to one or two months. Both descriptive statistics and logistic regression techniques were used to identify key characteristics of these brief users. The second set of analyses focused on clients who used services for three or more months. Regression techniques and hierarchical linear modeling procedures were used to identify and describe their patterns of respite use.

Of the 2193 clients using day care services, 640 were brief users and 1553 were extended users. Key characteristics of day care users are shown on Tables 2.3 and 2.4. Of the 2690 clients using in-home services 831 were short term users and 1859 were extended users. Characteristics of elders and caregivers using in-home services are shown in Tables 2.5 and 2.6.

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**TABLE 2.3 DAY CARE: ELDER CHARACTERISTICS** 

		are Users		Users	Exte	
	<b>2193</b> N	100% %	<b>640</b> N	29.2% %	<b>1553</b> N	70.8% %
*Race	IN	70		70		70
White	1111	50.7%	377	58.9%	734	47.3%
Black/African-American	722	32.9%	159	24.8%	563	36.3%
Hispanic/Latino	244	11.1%	67	10.5%	177	11.4%
Asian/Pacific Islander	83	3.8%	25	3.9%	58	3.7%
Native American/Alaskan	6	0.3%	3	0.5%	3	0.2%
Unknown	5	0.2%	9	1.4%	18	1.2%
*Geographic Location						
Urban	1046	47.7%	283	44.2%	763	49.1%
Rural	1002	45.7%	318	49.7%	684	44.0%
Unknown	145	6.6%	39	6.1%	106	6.8%
Average Income						
Under \$5,000	331	15.1%	89	13.9%	242	15.6%
\$5,000 - \$15,000	1255	57.2%	361	56.4%	894	57.6%
\$15,001 - \$30,000	319	14.5%	101	15.8%	218	14.0%
\$30,001 - \$50,000	50	2.3%	15	2.3%	35	2.3%
Over \$50,000	18	0.8%	5	0.8%	13	0.8%
Unknown	220	10.0%	69	10.8%	151	9.7%
Gender						
Male	734	33.5%	232	36.3%	502	32.3%
Female	1410	64.3%	396	61.9%	1014	65.3%
Unknown	49	2.2%	12	1.9%	37	2.4%
Marital Status						
Single/Divorced	124	5.7%	33	5.2%	91	5.9%
Married	832	37.9%	264	41.3%	568	36.6%
Widowed	1085	49.5%	299	46.7%	786	50.6%
Unknown	152	6.9%	44	6.9%	108	7.0%
*Living Arrangement						
Live Alone	277	12.6%	83	13.0%	194	12.5%
Live with Spouse	821	37.4%	265	41.4%	556	35.8%
Live with Children	827	37.7%	218	34.1%	609	39.2%
Other Unknown	233 35	10.6% 1.6%	57 17	8.9% 2.7%	176 18	11.3% 1.2%
*Total Number in House	hold					
Live Alone	277	12.6%	83	13.0%	194	12.5%
Elder + 1 other	953	43.5%	303	47.3%	650	41.9%
Elder + 2 others	423	19.3%	111	17.3%	312	20.1%
Elder + 3 or more	501	22.8%	124	19.4%	377	24.3%
Other/Unknown	39	1.8%	19	3.0%	20	1.3%
Number of Services Use	ed Prior to E	Entry				
0	802	36.6%	257	40.2%	545	35.1%
1 - 2	1091	49.7%	296	46.3%	795	51.2%
3 or more	300	13.7%	87	13.6%	213	13.7%

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

TABLE 2.3 DAYCARE: ELDER CHARACTERISTICS--Continued

	All Dayca	All Daycare Users		Users	Exte	Extended	
	2193	100%	640	29.2%	1553	70.8%	
	N	%	N	%	N	%	
Alzheimer's Disease							
Suspected	385	17.6%	91	14.2%	294	18.9%	
Diagnosed	1534	69.9%	464	72.5%	1070	68.9%	
Other	268	12.2%	70	10.9%	183	11.8%	
Unknown	6	0.3%	15	2.3%	5	0.3%	
Functional Level							
*Mean ADL (0 - 10)	3	3.1		3.4		3.0	
Mean IADL (0 - 16)	12	2.2	12.4		12.1		
*Mean ADL/IADL (0 - 26)	15	5.3	15.7		15.2		
Problem Behavior							
*Mean Score (0 - 45)	12.9		14.1		12.5		
Mean age	78	3.8	79.3		78.6		

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

#### **BRIEF USERS**

One important goal for agencies providing respite services is to provide services that are appropriate for the full range of caregivers. Most observers would agree that respite programs, especially publicly subsidized respite programs, should not systematically exclude any group of potential service users. Not surprising then, the issue of why some caregivers use respite services while others choose not to is of persisting interest to service planners, providers, and evaluators.

Just as there is no single type of "service user", non-users of respite are also of multiple types (Kosloski, Montgomery and Youngbauer, 2001). For example, there are caregivers who are unaware that such services exist. Others are aware of respite programs, but never inquire about them, nor utilize the services. There are also caregivers who might be viewed as "service seekers". These are individuals who inquire about the services, but never actually use them. Finally there are caregivers who use the services over a relatively short period of time and then, apparently, never use them again.

**TABLE 2.4 DAY CARE: CAREGIVER CHARACTERISTICS** 

	All Dayc	are Users	Brie	Users	Exte	nded
	2193	100%	640	29.2%	1553	70.8%
	N	%	N	%	N	%
Gender						
Male	506	23.1%	143	22.3%	363	23.4%
Female	1595	72.7%	468	73.1%	1127	72.6%
Unknown	92	4.2%	29	4.5%	63	4.1%
*Relationship to Elder						
Spouse	709	32.3%	237	37.0%	472	30.4%
Adult child / child-in-law	1086	49.5%	299	46.7%	787	50.7%
Other relative	221	10.1%	62	9.7%	159	10.2%
Friend	52	2.4%	10	1.6%	42	2.7%
Professional care manager	82	3.7%	20	3.1%	62	4.0%
Self	12	0.5%	7	1.1%	5	0.3%
Unknown	31	1.4%	5	0.8%	26	1.7%
Marital Status						
Single/Divorced	269	12.3%	76	11.9%	193	12.4%
Married	1477	67.4%	450	70.3%	1027	66.1%
Widowed	129	5.9%	32	70.3 <i>%</i> 5.0%	97	6.2%
Unknown	318	5.9% 14.5%	32 82	12.8%	236	15.2%
	310	14.570	0Z	12.070	200	13.270
Services Used						
Day Care only	1679	76.6%	483	75.5%	1196	77.0%
Day Care and In-home	514	23.4%	157	24.5%	357	23.0%
*Age (in years)						
44 or less	317	14.5%	82	12.8%	235	15.1%
45 - 54	352	16.1%	97	15.2%	255	16.4%
55 - 64	393	17.9%	111	17.3%	282	18.2%
65 - 74	350	16.0%	102	15.9%	248	16.0%
75 - 84	274	12.5%	96	15.0%	178	11.5%
Over 84	38	1.7%	12	1.9%	26	1.7%
Unknown *Mean age	469	21.4% 9.1	140	21.9% 60.3	329	21.2% 3.6
_	J.	J. I		0.5	50	5.0
Education						
Less than high school	427	19.5%	134	20.9%	293	18.9%
Completed high school	625	28.5%	182	28.4%	443	28.5%
Vocational training	115	5.2%	32	5.0%	83	5.3%
Attended college	390	17.8%	114	17.8%	276	17.8%
College graduate	379	17.3%	101	15.8%	278	17.9%
Graduate work	75	3.4%	17	2.7%	58	3.7%
Unknown	182	8.3%	60	9.4%	122	7.9%
*Employment						
Full-time	646	29.5%	159	24.8%	487	31.4%
Part-time	213	9.7%	54	8.4%	159	10.2%
Unemployed	494	22.5%	138	21.6%	356	22.9%
Retired	635	29.0%	217	33.9%	418	26.9%
Other	118	5.4%	40	6.3%	78	5.0%
Unknown	87	4.0%	32	5.0%	55	3.5%

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

TABLE 2.4 DAYCARE: CAREGIVER CHARACTERISTICS--Continued

	All Dayc	are Users	Brief	Users	Exte	nded
	2193	100%	640	29.2%	1553	70.8%
	N	%	N	%	N	%
Average income						
Under \$5,000	278	12.7%	90	14.1%	188	12.1%
\$5,000-\$15,000	567	25.9%	170	26.6%	397	25.6%
\$15,001-\$30,000	475	21.7%	134	20.9%	341	22.0%
\$30,001-\$50,000	195	8.9%	52	8.1%	143	9.2%
Over \$50,000	78	3.6%	18	2.8%	60	3.9%
Unknown	600	27.4%	176	27.5%	424	27.3%
<b>Driving Distance from Elder</b>	(in minut	es)				
Lives in same household	1805	82.3%	517	80.8%	1288	82.9%
1 - 10	184	8.4%	52	8.1%	132	8.5%
11 - 30	109	5.0%	38	5.9%	71	4.6%
Over 30	21	1.0%	5	0.8%	16	1.0%
Other/Unknown	74	3.4%	28	4.4%	46	3.0%
Length of caregiving before	progran	n entry (in m	onths)			
0 - 6	351	16.0%	91	14.2%	260	16.7%
7 - 12	220	10.0%	71	11.1%	149	9.6%
13 - 24	367	16.7%	105	16.4%	262	16.9%
25 - 36	290	13.2%	80	12.5%	210	13.5%
37 - 72	379	17.3%	96	15.0%	283	18.2%
72 or more	336	15.3%	111	17.3%	225	14.5%
Unknown	250	11.4%	86	13.4%	164	10.6%
Mean length of caregiving	40	0.0	4	1.5	39	9.4

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

Knowledge about this last group of caregivers (i.e., those who are brief users) is particularly important for two reasons. First, brief users constitute a substantial proportion of all service users. Brief users have been shown to comprise from 24 to 29% of all respite users (Cox, 1997; Zarit, Stephens, Townsend, Greene and Leitsch, 1999). As such, they contribute significantly to the monthly caseload of users and consequently providers must reserve space for them. But since brief users fail to return for services, the reservation of space for them constitutes a very inefficient allocation of resources. In this study, approximately 30% of the families in the sample used respite services for two months or less. Second, and more importantly, brief users have, by their behavior, indicated a need for respite services. Whereas non-users and seekers may simply not have perceived a need for outside assistance, the same cannot be said for brief users. In fact, it is hard to escape the impression that the respite program has somehow failed these individuals. That is, since the respite service was actually tried by the caregiver and abruptly discontinued, it was apparently found lacking in some way or otherwise did not meet

**TABLE 2.5 IN-HOME: ELDER CHARACTERISTICS** 

	All In-Ho	All In-Home Users		Users	Extended	
	2690	100%	831	30.9%	1859	69.1%
	N	%	N	%	Ν	%
*Race						
White	1649	61.3%	533	64.1%	1116	60.0%
Black/African-American	828	30.8%	221	26.6%	607	32.7%
Hispanic/Latino	131	4.9%	40	4.8%	91	4.9%
Asian/Pacific Islander	44	1.6%	17	2.0%	27	1.5%
Native American/Alaskan	10	0.4%	5	0.6%	5	0.3%
Unknown/other	28	1.0%	11	1.3%	13	0.7%
Geographic Location						
Urban	907	33.7%	276	33.2%	631	33.9%
Rural	1623	60.3%	514	61.9%	1109	59.7%
Unknown	160	5.9%	41	4.9%	119	6.4%
Average Income						
Under \$5,000	385	14.3%	126	15.2%	259	13.9%
\$5,000 - \$15,000	1508	56.1%	460	55.4%	1048	56.4%
\$15,001 - \$30,000	476	17.7%	138	16.6%	338	18.2%
\$30,001 - \$50,000	71	2.6%	22	2.6%	49	2.6%
Over \$50,000	20	0.7%	8	1.0%	12	0.6%
Unknown	230	8.6%	77	9.3%	153	8.2%
*Gender						
Male	915	34.0%	306	36.8%	609	32.8%
Female	1728	64.2%	512	61.6%	1216	65.4%
Unknown	47	1.7%	13	1.6%	34	1.8%
Marital Status						
Single/Divorced	123	4.6%	31	3.7%	92	4.9%
Married	1270	47.2%	393	47.3%	877	47.2%
Widowed	1153	42.9%	361	43.4%	792	42.6%
Unknown	144	5.4%	46	5.5%	98	5.3%
Living Arrangement						
Live Alone	426	15.8%	131	15.8%	295	15.9%
Live with Spouse	1251	46.5%	385	46.3%	866	46.6%
Live with Children	817	30.4%	255	30.7%	562	30.2%
Other	180	6.7%	54	6.5%	126	6.8%
Unknown	16	0.6%	6	0.7%	10	0.5%
<b>Total Number in House</b>						
Live Alone	426	15.8%	131	15.8%	295	15.9%
Elder + 1 other	1442	53.6%	458 436	55.1%	984	52.9%
Elder + 2 others Elder + 3 or more	464 338	17.2% 12.6%	136 99	16.4% 11.9%	328 239	17.6% 12.9%
Other/Unknown	20	0.7%	7	0.8%	13	0.7%
Number of Services Us	ed Prior to F					
0	935	34.8%	304	36.6%	631	33.9%
1 - 2	1416	52.6%	430	51.7%	986	53.0%
3 or more	339	12.6%	97	11.7%	242	13.0%

 $<sup>^{*}</sup>$  Difference between the brief users and the extended group significant at p <= .05

TABLE 2.5 IN-HOME: ELDER CHARACTERISTICS--Continued

	All In-Ho	me Users	Brief	Users	Extended	
	2690	100%	831	30.9%	1859	69.1%
	N	%	N	%	Ν	%
Alzheimer's Disease						
Suspected	434	16.1%	117	14.1%	317	17.1%
Diagnosed	2017	75.0%	648	78.0%	1369	73.6%
Other	235	8.7%	65	7.8%	170	9.1%
Unknown	4	0.1%	1	0.1%	3	0.2%
Functional Level						
*Mean ADL (0 - 10)	4	.5	4	4.2	4	.6
Mean IADL (0 - 16)	13	3.1	13.1		13.0	
Mean ADL/IADL (0-26)	17.5		17.3		17.6	
Problem Behavior						
Mean Score (0 - 45)	13	3.0	1	3.3	12	2.9
Mean age	80	0.0	80.1		80.0	

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

**TABLE 2.6 IN-HOME: CAREGIVER CHARACTERISTICS** 

	All In-Home Users		Brie	Users	Extended	
	2690	100%	831	30.9%	1859	69.1%
	N	%	N	%	N	%
Gender						
Male	719	26.7%	214	25.8%	505	27.2%
Female	1911	71.0%	604	72.7%	1307	70.3%
Unknown	60	2.2%	13	1.6%	47	2.5%
Relationship to Elder						
Spouse	1084	40.3%	341	41.0%	743	40.0%
Adult child / child-in-law	1183	44.0%	366	44.0%	817	43.9%
Other relative	276	10.3%	77	9.3%	199	10.7%
Friend	68	2.5%	24	2.9%	44	2.4%
Professional care manager	25	0.9%	11	1.3%	14	0.8%
Self	5	0.2%	0	0.0%	5	0.3%
Unknown	49	1.8%	12	1.4%	37	2.0%
Marital Status						
Single/Divorced	308	11.4%	92	11.1%	216	11.6%
Married	1902	70.7%	599	72.1%	1303	70.1%
Widowed	198	7.4%	65	7.8%	133	7.2%
Unknown	282	10.5%	75	9.0%	207	11.1%
Services Used						
In-home Only	2176	80.9%	679	81.7%	1497	80.5%
In-home and Day Care	514	19.1%	152	18.3%	362	19.5%

<sup>\*</sup> Difference between the brief users and the extended group significant at p <= .05

TABLE 2.6 IN-HOME: CAREGIVER CHARACTERISTICS--Continued

	All In-Ho	me Users	Brief	Users	Exte	ended
	2690	100%	831	30.9%	1859	69.1%
Age (in years)	N	%	N	%	N	<u>%</u>
44 or less	300	11.2%	87	10.5%	213	11.5%
45 - 54	415	15.4%	130	15.6%	285	15.3%
55 - 64	458	17.0%	141	17.0%	317	17.1%
65 - 74	520	19.3%	151	18.2%	369	19.8%
75 - 84	492	18.3%	138	16.6%	354	19.0%
Over 84	106	3.9%	41	4.9%	65	3.5%
Unknown	399	14.8%	143	17.2%	256	13.8%
Mean age		2.6		62.7		2.5
Education						
Less than high school	584	21.7%	167	20.1%	417	22.4%
Completed high school	849	31.6%	272	32.7%	577	31.0%
Vocational training	129	4.8%	34	4.1%	95	5.1%
Attended college	387	4.6% 14.4%	3 <del>4</del> 127	15.3%	260	14.0%
College graduate	389	14.4%	134	16.1%	255	13.7%
Graduate work	96	3.6%	30	3.6%	233 66	3.6%
Unknown	256	9.5%	67	3.0% 8.1%	189	10.2%
*Employment						
Full-time	604	22.5%	174	20.9%	430	23.1%
Part-time	251	9.3%	95	11.4%	156	8.4%
Unemployed	600	22.3%	198	23.8%	402	21.6%
Retired	1029	38.3%	311	37.4%	718	38.6%
Other	151	5.6%	37	4.5%	114	6.1%
Unknown	55	2.0%	16	1.9%	39	2.1%
Average income						
Under \$5,000	399	14.8%	126	15.2%	273	14.7%
\$5,000-\$15,000	786	29.2%	247	29.7%	539	29.0%
\$15,001-\$30,000	600	22.3%	180	21.7%	420	22.6%
\$30,001-\$50,000	203	7.5%	65	7.8%	138	7.4%
Over \$50,000	72	2.7%	27	3.2%	45	2.4%
Unknown	630	23.4%	186	22.4%	444	23.9%
<b>Driving Distance from El</b>	<b>der</b> (in minu	tes)				
Lives in same household	2153	80.0%	669	80.5%	1484	79.8%
1 - 10	238	8.8%	79	9.5%	159	8.6%
11 - 30	155	5.8%	47	5.7%	108	5.8%
Over 30	40	1.5%	13	1.6%	27	1.5%
Other/Unknown	104	3.9%	23	2.8%	81	4.4%
*Length of caregiving be	fore progra	ı <b>m entrv</b> (in r	months)			
0 - 6	386	14.3%	141	17.0%	245	13.2%
7 - 12	298	11.1%	102	12.3%	196	10.5%
13 - 24	427	15.9%	137	16.5%	290	15.6%
25 - 36	346	12.9%	105	12.6%	241	13.0%
37 - 72	539		150		389	
		20.0%		18.1% 15.0%		20.9%
72 or more Unknown	473	17.6%	132	15.9%	341 157	18.3%
UTIKTIOWII	221	8.2%	64	7.7%	157	8.4%

 $<sup>^{\</sup>star}$  Difference between the brief users and the extended group significant at p <= .05

his or her current needs or expectations. From this perspective, an analysis of brief users should be an important part of any evaluation of respite services, because they may constitute a population of caregivers that is not being served adequately or equitably. The purpose of this analysis, then, was to examine the characteristics of brief users of respite services and, in particular, to identify the factors associated with brief use in order to determine whether there is something about the manner in which services are being offered that may disadvantage this group of potential users.

#### **Previous Research**

At least two investigations have examined the phenomenon of brief use of respite services. A groundbreaking study by Cox (1997) used Andersen's (1968) behavioral model to identify factors potentially related to respite use. The behavioral model identifies three types of individual characteristics as the primary determinants of service use: predisposing, enabling, and need factors. The predisposing variables in the study by Cox (1997) included sociodemographic characteristics of the elder and caregiver, length of time and hours spent caregiving, and the caregiver's relationship to the elder. Enabling variables encompassed resources that might affect access to respite and included the caregiver's informal relationship with others who might provide expressive or instrumental support as well as the use of other formal services. Need on the part of the care recipient included ADL status, level of cognitive impairment, and behavior problems. Need on the part of the caregiver included anxiety, depression, burden, and the extent to which the caregiver felt that he or she had benefited from the caregiving role. The results indicated that caregivers who used respite services for a period of six months or less were more likely to be White than were persons using services for a longer period. No other differences were identified.

Two issues arise from the study by Cox (1997) that affect the interpretability of her findings. First, the study sample included both users of day care and in-home services. Although both services are intended to provide relief to caregivers, these services obviously differ from one another in important ways. As data from the ADDGS program will illustrate, day care and inhome respite also serve different populations of users. Failure to differentiate between these services may have obscured important differences in reasons for non-use. Second, Cox defined brief use as the use of respite for six months or less. In the career of a respite user, six

months is actually a substantial period of time. For example, the average length of use of respite among all clients in the ADDGS program is only ten months. It seems likely that the definition of brief use employed by Cox allowed for the inclusion of a large number of clients at late stages in the caregiving career. For example, over half of the brief users in the study by Cox said that the reason they stopped using respite was because they had placed their relative in a nursing home. An additional one-third reported stopping because of the death of the elder. In short, over 80% of the brief users could actually be characterized as conventional respite users; they simply represented caregivers who were in later stages of the caregiving career. This group of individuals is likely to be very different from persons who discontinue respite services, yet continue in their caregiving role.

In a more recent study, Zarit, Stephens, Townsend, Greene and Leitsch (1999) attempted to correct both of these limitations. First, they focused only on use of adult day care. Second, they restricted the definition of brief use to include individuals who used services for three months or less. This definition of brief use reduced the proportion of the sample that consisted of brief users sample who stopped service use because of institutionalization of the care recipient. Only 35% of the brief users in the study by Zarit and his colleagues terminated services due to placement in contrast to 50% of the sample in the study by Cox.

The analyses conducted by Zarit and his colleagues (1999) included potential covariates of brief respite use that were derived from the stress process model of caregiving (Pearlin, Mullin, Semple and Skaff, 1990). In this model, caregiving is viewed as a continuing process of stress and adaptation in which personal and social resources are used, as necessary, to contain the effects of primary stressors. Based on this model, covariates of extended use and, conversely, brief use, were hypothesized to include social resources (represented by socio-demographic characteristics), severity of patients' symptoms, and caregivers' appraisals of stressors, and their own levels of well-being. Using this approach, Zarit and his colleagues identified a number of correlates of brief use. Specifically, brief users had less formal education, were likely to be a spouse caregiver, more likely to be male, and have lower levels of depressive symptoms. In addition, care receivers tended to have higher ADL impairment and more behavior problems

A potentially serious limitation of both the studies by Cox and by Zarit et al. is the almost

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exclusive focus on individual characteristics of either the caregiver or the elder, in their explanations for brief use. Respite is a service that is similar to other consumer-driven services in the sense that decisions to use the service almost certainly are influenced by characteristics of the service itself. For example, sustained service use is likely to be influenced by whether the respite is provided by a paid professional or a volunteer, the availability of a health component, the fee structure, and whether there is a limit to the amount of respite that can be used.

Program characteristics are likely to have differential appeal to caregivers, depending upon each caregiver's specific needs and circumstances. Although respite can take many forms, most respite programs are of two general types: adult day care (ADC) and in-home respite. ADC typically occurs in a group setting, is primarily custodial, does not provide intensive medical care, involves structured activities for relatively high functioning individuals, and affords little flexibility in scheduling. In contrast, in-home respite may have greater appeal to caregivers who care for patients with more serious health and behavioral impairments, and for those who need greater flexibility in scheduling. It seems likely that characteristics of respite programs will affect users differently, depending upon whether they are using ADC or in-home respite. For example, failure to provide skilled nursing care is likely to have a greater adverse effect on users of in-home respite who are caring for elders with greater physical impairment than it would on users of ADC.

# <u>Hypothesized Models of Respite Use</u>

A comprehensive model of brief respite use, then, should include both characteristics of the users and characteristics of the services. Moreover, the factors related to brief use are likely to vary depending upon the type of respite service under consideration, since different services, such as ADC and in-home respite, attract different populations of users. Consistent with this understanding, both individual and provider characteristics are explored as factors associated with brief use of respite services.

#### Characteristics of the Individual

Seven characteristics of the caregiver and elder that have been found to be related to brief use in previous research were identified for inclusion in these analyses: ethnicity, education, relationship to the patient, gender, employment status, ADL/IADL, and problem behaviors.

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Both Cox (1997) and Zarit et al. (1999) reported that White caregivers were more likely to be brief users. Since minority status is typically associated with an under use of services (see Wolinsky et al., 1990), this relationship may seem counter intuitive. In the context of the ADDGS, however, such is not the case. Since the goal is to serve traditionally under served populations, particularly minority and rural caregivers, a special effort has been made to attract and retain minority caregivers.

Previous research has also found that lower education levels, being a spouse caregiver, and being a male caregiver are all to be associated with brief use of ADC (Zarit et al., 1999). Of these variables, only relationship status (i.e., spouse) affords a clear explanation for its effects. As Zarit and his colleagues note, spouses are likely to be reluctant to use respite on a continuous basis due to the socio-emotional aspects of their role. That is, they have stronger feelings of obligation and affection and suffer greater personal and social sanctions for turning the care for their spouse over to a formal provider. The role of education and gender are less clear, although males may be more likely to institutionalize their spouse than female caregivers.

Stressors or need factors such as the elder's need for ADL assistance and the extent of problem behaviors have also been shown to be related to brief use of ADC (Zarit et al., 1999), although logic would suggest that they have greater relevance to sustained use of ADC than to in-home respite. For example, increased need for ADL/IADL assistance frequently exceeds the capacity of many ADC programs, which may lack medical facilities or staff with medical training. Also, as ADL/IADL impairment increases, it also becomes more difficult for caregivers to get the client ready for the ADC program. Elders who exhibit problem behaviors may similarly tax the resources of the day care staff and may be perceived as being unlikely to benefit from programming. Consequently, these factors are likely to be associated with brief use of ADC, but not with in-home respite.

Evidence concerning the relationship between employment status of the caregiver and brief respite use is equivocal. On the one hand, it was found to be unrelated to brief use in the study by Cox (1997). On the other hand, it has been suggested to be an important covariate in understanding the manner in which the relationship of the caregiver to the elder is related to brief use of ADC (Zarit et al., 1999). Specifically, since adult children are more likely to be employed than spouses, respite use allows them to remain employed and still keep their parent

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at home. From this perspective, employment status serves as a potentially important control variable in understanding generational differences in brief use.

# Characteristics of the Respite Program

In addition to characteristics of the service users, a number of characteristics of the respite service were hypothesized to be related to brief use. These factors include: service capitation, fee structure, staffing patterns, availability of health or personal care, hours of operation or service availability, and type of service.

Many programs have policies that limit the amount of respite that can be used by any family. Depending upon the individual circumstances of the caregiver, when the amount of respite available is strictly limited, its attractiveness to caregivers may be diminished.

Cost was also hypothesized to affect brief use. Zarit and his colleagues (1999) found that non-subsidized respite was associated with brief use at the bivariate, but not the multivariate, level. Although a subsidy can be expected to lessen the impact of cost on brief use, a subsidy is unlikely to remove the total impact of service cost because of the variability in the manner in which a subsidy can be implemented. For example, some programs have a set fee structure or a percentage co-payment. Other programs use a sliding fee scale based on the caregiver's income or accept voluntary contributions. Clearly, even when subsidized, some programs can establish very restrictive fee structures. From this perspective, it seems reasonable to expect that fee structures will impact decisions about service use.

Staffing refers to whether the respite workers are paid professionals or volunteers. Professional caregivers are more likely to have specialized training and to be able to handle difficult cases involving the provision of routine medical care or dealing with problem behaviors. It was hypothesized that staffing would be more relevant for in-home respite programs than for ADC for two reasons. First, in general, in-home clients tend to be more impaired as indicated by greater ADL impairment or have more problem behaviors than do most clients of adult day care. Thus, when in-home respite workers are paid employees, caregivers will be less likely to be brief users. In contrast, since adult day care tends to serve clients with lower levels of impairment, whether the respite worker is a paid professional versus a volunteer is less likely to

matter. Additionally, an ADC setting affords the simultaneous presence of both paid and volunteer workers. In contrast, a volunteer may be the only worker present in an in-home setting.

A related characteristic of the respite service involves the provision of some health care services. A number of programs provide a health care component using trained professional personnel. The ability to receive health care services is likely to be most relevant to users of inhome respite who are likely to be caring for AD patients with higher levels of impairment. However, in some states Medicaid reimbursement is only available for persons using Adult Day Health services as opposed Social Day Health services. This reimbursement factor may also influence use patterns.

In the case of adult day care, whether the program is based on a group model as opposed to a traditional day care model is also likely to affect sustained use. Group day models tend to use volunteers and offer limited amounts of respite (e.g., one or two afternoons per week). When the needs of caregivers exceed the level of services offered by group day programs, caregivers are more likely to end up as brief users.

A similar circumstance occurs for in-home respite. Programs with greater flexibility will undoubtedly accommodate more potential users. Thus, when the hours during which services are offered are flexible, and can be adapted to meet the needs of clients, instances of brief use are likely to decline. Similarly, since in-home respite users are more likely to require personal care for their patients, whether the in-home program provides such care is likely to alter its utility to potential users. Specifically, when personal care is provided, the probability of brief use can be expected to decrease.

#### **Description of Measures**

#### Demographic variables

As noted earlier, demographic information was gathered at the time of client intake.

Demographic variables included in this analysis are *ethnicity*, *relationship of the caregiver to* 

the care recipient, sex of the caregiver, and employment status. For this analysis caregiver's employment status was categorized as full time employment, part time employment or not working.

# Measures of Primary Stressors

Measures of the client's functional status and problem behavior were included as indicators of primary stressors. The client's functional status was measured with a 13-item composite measure of Activities of Daily Living (ADL) and Instrumental Activities of Daily living (IADL) that includes items from the Katz et al. (1963) ADL scale. Problem behaviors were measured with the 15-item inventory used by Pearlin and his colleagues (1990).

#### Measures of Programmatic Characteristics

Seven measures of programmatic characteristics were included in the analyses. Four of these measures were gathered for both day care and in-home programs. The measure of *staffing patterns* indicates the type of workers employed. This is a dichotomous variable indicating whether the program was staffed solely by paid staff or by a combination of paid and volunteer employees. The *capitation of hours* is the maximum number of hours that a program will provide to a single client in a year. For in-home providers the scale ranged from 50 to 1,920 hours annually. For day care providers, the scale ranged from 80 to 2,880 hours annually. The availability of services related to *health care* was measured with a dichotomous variable. Providers of respite services used four different types of fee structures. These *fee structures* included: co-payment, sliding fee scale, set fee scale, and voluntary contribution. Each of these fee structures was coded into a dichotomous variable.

The *type of program* classified the kind of Adult Day Care program was provided. Day Care Centers either operated on the Brookdale Group Day Care model which provides three to four hours of care once or twice a week or they operated for six or more hours four to five days a week. Some providers operated both types of services. Finally, a dichotomous variable, *flexibility of operating hours*, was created to reflect whether the hours of operation were flexible and could be adapted to meet the needs of clients.

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# **Data Analyses**

Two types of analyses were used to evaluate factors that were associated with brief use of respite services. First, the demographic and functional characteristics of caregivers and elders identified as brief users (i.e., service use duration of two months or less) were compared to those of persons identified as extended users (service use duration greater than two months). Second, logistic regression procedures were used to examine the relationship between brief use and client and provider characteristics. These regressions were conducted in a stepwise procedure. In the first step, only the set of socio-demographic variables were entered into the model. In the second step, the set of programmatic characteristics were entered to determine if they added significantly to the model.

# **Brief Users of Day Care**

# Comparison of Characteristics of Brief Users to Extended Users

Brief day care users differed significantly from extended users on numerous characteristics including elder's race, geographic location, living arrangement, number in household, activities of daily living (ADL), problem behaviors, caregiver's relationship to elder, and caregiver's employment status. The characteristics of elders using day care for both the brief and extended user groups are reported in Table 2.3. Black/African-Americans were less prevalent in the brief user sample (24.8%) than in the extended sample (36.3%) as were Hispanics who comprised 10.5% of the brief users and 11.4% of the extended users. In contrast, the extended user sample included a lower proportion of Whites (47.3%) than did the brief user sample (58.9%). Brief users were more likely than elders in the extended user group to reside in rural areas (49.7% vs. 44.0%) and less likely to live urban locations (44.2% vs. 49.1%). A larger proportion of the brief user group than the extended sample lived with their spouse (41.4% vs. 35.8%) and a smaller number lived with their adult children (34.1% vs. 39.2%). Consistent with this pattern of living arrangement, brief users were also more likely than persons in the extended sample to live with only one other household member (47.3% to 41.9%). Finally there was a significant difference between the two samples in the mean scores for impairment of activities of daily living (ADL) and problem behaviors.

Characteristics of caregivers included in the day care sample are shown in Table 2.4. Spouses

were more prevalent as caregivers for the brief user group than for the extended group (37.0% vs. 30.4%) and adult children were less prevalent for the brief user group (46.7% vs. 50.7%). Consistent with this greater prevalence of spouse caregivers in brief user group, a greater proportion of brief users were married (70.3%) than was the case in the extended group (66.1%) and a slightly higher proportion of the extended group was widowed (6.2% vs. 5.0%). Finally, caregivers of brief users were less likely than those in the extended group to be employed full-time (24.8% vs. 31.4%), and more likely to be retired (33.9% vs. 26.9%).

# **Predictors of Brief Use of Day Care**

As shown in Table 2.7 the multivariate logistic regression analysis, the set of socio-demographic variables added vastly to the predictive efficacy of the model of brief use of ADC (*Chi-square* = 50.79, df=10). The regression coefficient for each variable is also shown in Table 2.7 along with its standard error. In reasonably large samples, such as the present, the test of whether the regression coefficient departs significantly from zero approximates a z-test. Thus, coefficients approximately twice the size of the standard error or greater are considered statistically significant. The exact probability level of each b/SE ratio under the null hypothesis of no effect (i.e., the coefficient = 0) is also given. The values for Exp(B) in the right-hand column are antilogged logit coefficients that indicate the relative odds of being classified as a brief user versus a longer user. These values are shown only for the coefficients that attained statistical significance. Values of Exp(B) greater than 1 indicate that higher scores on the predictor variable increase the probability of being in the brief user group; values less than 1 indicate a decreased likelihood.

Three variables from the set of individual characteristics had significant unique effects on the probability of being a brief user. Consistent with the earlier findings by Cox (1997), ethnicity emerged as a significant predictor of brief use of ADC. Both Black/African-Americans and Latino/Hispanics were less likely than Whites to be brief users. Also, as hypothesized, when the number of problem behaviors increased, so did the likelihood of being a brief user of ADC.

TABLE 2.7 MODEL OF BRIEF-TERM USE OF DAY CARE

	Demographics Only (N = 2193)			Full Model (N = 2193)		
	b/SE	Sig.	•	b/SE		Exp(B)
Black/African-American	60/.12	.00	.55	56/.14	.00	.57
Hispanic/Latino	28/.17	.11		36/.19	.06	
Caregiver Education	03/.04	.34		04/.04	.26	
Child Caregiver	.08/.16	.60		.05/.16	.74	
Spousal Caregiver	.18/.18	.31		.15/.18	.42	
Elder's Sex	.01/.13	.93		.04/.13	.77	
Composite ADL/IADL	01/.01	.31		01/.01	.29	
Problem Behaviors	.03/.01	.00	1.03	.03/.01	.00	1.03
Fulltime Employed	21/.13	.11		20/.13	.14	
Parttime Employed	19/.18	.29		19/.18	.29	
Staffing				.03/.07	.73	
Capitation of Hours				02/.01	.03	.98
Health Care Component				.29/.13	.02	1.33
Copayment Required				.56/.44	.20	
Sliding Fee Scale				.29/.17	.09	
Set Fee Scale				22/.21	.28	
Constant	85/.33	.01	.43	99/.37	.01	.37
Chi-Square Change Degrees of Freedom	50.79 10	.00		2.51 6	.05	

When the set of program characteristics were added to the model of brief use of ADC, there was a significant increase in the predictive efficacy of the model (Chi-square = 12.51, df= 6). Two programmatic variables emerged with significant unique effects: capitation of service hours and the presence of a health care component. When the amount of respite care that a

caregiver could use was strictly limited, the probability that the caregiver would become a brief user increased. Surprisingly, when there was a health care component to the ADC, the probability of brief use increased as well.<sup>1</sup>

# **Brief Users of In-Home Respite**

# Comparison of Characteristics of Brief Users to Extended Users

Characteristics of elders and caregivers included in the in-home sample are shown in Tables 2.5 and 2.6. Notably, elder brief in-home users differed significantly from the extended group on three variables: race, gender, and ADL measure. White elders were more likely to be in the brief user group (64.1% to 60%) while Black/African-Americans were more likely to be in the extended user group (26.6% to 32.7%). The proportion of brief users who were male (36.8%) was slightly higher than that of the extended sample (32.8%). Female elders were more likely to be in the extended group (65.4% to 61.6%) and the difference was statistically significant. Additionally, elders in the brief user group had significantly higher functioning ADL levels than those in the extended group. Caregivers in the brief user group also varied significantly from those in the extended group only on length of time caregiving before enrolling in the demonstration program. Caregivers in the brief user group averaged 39.4 months of prior caregiving, while caregivers in the extended user group had provided care an average of 43.8 months.

Table 2.8 shows the multivariate logistic regression analysis of brief use of in-home respite on the sets of predictors. The set of socio-demographic variables did not add significantly to the predictive efficacy of the model of brief use of in-home respite (Chi-square = 17.75, df = 10). However, the race variable for Blacks did obtain significance indicating that Blacks were less likely to be brief users of in-home health service. Furthermore, when the set of variables reflecting program characteristics were added to the model, the variables Black and Hispanic both became statistically significant indicating a lower probability of brief use for minority groups.

TABLE 2.8 MODEL OF BRIEF-TERM USE OF IN-HOME RESPITE

	Demographics Only (N = 2690)				II Mod = 269	
	b/SE	Sig.	Exp(B)	b/SE		Exp(B)
Black/African-American	23/.11	.04	.79	24/.13	.06	
Hispanic/Latino	05/.22	.82		79/.27	.00	.45
Caregiver Education	.03/.03	.42		.03/.03	.43	
Child Caregiver	.15/.16	.35		.12/.16	.46	
Spousal Caregiver	.02/.18	.91		.01/.18	.96	
Elder's Sex	19/.11	.10		22/.12	.06	
Composite ADL/IADL	01/.01	.28		01/.01	.45	
Problem Behaviors	.01/.01	.14		.01/.01	.26	
Fulltime Employed	10/.14	.48		04/.14	.80	
Parttime Employed	.26/.16	.11		.32/.17	.05	1.38
Staffing				34/.05	.00	.72
Capitation of Hours				.01/.01	.42	
Health Care Component				66/.16	.00	.52
Copayment Required				.34/.15	.02	1.41
Sliding Fee Scale				.18/.12	.15	
Set Fee Scale				58/.20	.00	.56
Constant	54/.33	.10		.5/.40	.06	
Chi-Square Change Degrees of Freedom	17.75 10	.06		70.59 6	.00	

When the set of program characteristics were added to the model of brief use of in-home services, there was a significant increase in the predictive efficacy of the model (Chi-square = 70.59, df = 6). Four programmatic variables emerged with significant unique effects: type of staffing, the presence of a health care component, required co-pay, and a set fee scale. When an all paid staff was used (i.e., no volunteers), brief use was less likely. Similarly, if the in-home program contained a health care component, the probability of brief use decreased. Finally, relative to voluntary fee structures, co-pay structures were associated with brief use while a set-fee structure was associated with extended use.

# **Discussion**

#### Brief Use of Day Care

The findings from the logistic analyses reveal a profile that suggests that day care use is most desired for clients with limited impairment. First, the positive relationship between brief user status and problem behaviors suggests that day care is most appropriate for dementia clients who do not exhibit a high degree of problem behaviors. This likely reflects the limited capacity of day care providers to care for persons with problem behaviors. At the same time, the positive relationship between the availability of health care services and brief use is a bit perplexing. It may be that persons with limited functional and mental impairment best suited to day care use. Even with the availability of health care services, it may be difficult for caregivers to fully utilize day care when the functional status of the elder is too limited. This conclusion is consistent with anecdotal reports that caregivers often find the difficulty of getting the client ready for day care too high of a price to pay for the limited relief that they will gain.

The findings also indicate that ethnicity matters--at least in the context of these demonstration data. Black/African-Americans are less likely to be brief term users of day care. The same pattern holds for Hispanic users, although the effect was less consistent. Stated conversely, Black/African-Americans and Hispanics are more likely to continue using day care after initial use. This pattern may reflect the success of the ADDGS demonstration to promote programs that more effectively serve these traditionally under-served populations.

#### **Brief Use of In-Home Respite**

The relationships observed between the individual covariates and brief respite use of in-home care is intuitively understandable if in-home care is viewed as the preference for the clients who are most impaired. For example, if the respite program employs paid workers, who tend to be better trained and more reliable than volunteers, caregivers are less likely to be brief-term users. For caregivers needing regular, scheduled relief, this pattern makes sense. In turn, if the in-home program offers health care services, clients are more likely to extend their use of services. That is, they are more likely to find the service useable for a more extended period of time.

Initially, one would logically expect caregivers to prefer programs with voluntary fees rather than mandatory set fee structure. However, voluntary fees alone do not offset programs that fail to meet the perceived needs of caregivers. In these data, programs with voluntary fees are significantly correlated with agencies that do not offer assistance with household tasks or personal care. That is, brief user status is a product of insufficient formal care, not voluntary fee structures. Additionally, set fee structures provide prospective users clear guidelines as to cost that allow them to make informed decisions and financial plans accordingly.

Brief users of in-home respite appear to have greater need for professional health and household assistance. In these data, the status of brief user is primarily a product of agency programming, as opposed to a product of elder and caregiver characteristics. The picture that emerges from these findings is one in which program characteristics shape patterns of in-home use, or more precisely, discontinued use. This finding is of particular interest because it provides clues to ways that programs might be altered to encourage continued use of services. Programs that offer assistance with household tasks and personal care, particularly those staffed by paid professionals, appear to be most useful to these caregivers. Thus, brief term users of in-home respite may constitute a sub-population of caregivers with unmet needs unlike those of continuous users.

## PATTERNS OF RESPITE USE OVER TIME

# Reduction of Study Population for Data Analyses

Data for 1148 day care clients and 1432 in-home clients were analyzed to identify profiles of extend respite use. To ensure an accurate and complete representation of each individual's trajectory of service use, data were included only for those clients who had completed their participation in the ADDGS program. For example, a client who is in the first month of service use could either stop (and become classified as a brief user) or continue use for an indeterminate amount of time. Since it is impossible to know which pattern will occur in advance, accurate classification is impossible. Similarly, including individuals who are at some unknown point in their spell of use would likely result in under estimating their total use for one or more of the definitions of "use" employed in this study. Therefore, analyses were limited to clients for whom complete data were available.

Although attempts were made to collect current care status information on every family in the sample, this information was not available for 669 cases (15.4%). Current care status was available for 3759 clients (84.6%). The majority of these (1202 elders, 27.5%) had been institutionalized, 823 elders (18.8%) had died, and 81 elders (4.1%) had moved. Additionally, 180 elders (4.1%) had discontinued services, 9 elders (0.2%) had become inappropriate for services (i.e., inappropriate behavior in day care settings), 593 elders (13.6%) had begun using services outside of the demonstration, and 712 elders (16.3%) were still using ADDGS supported services.

Hence, of the 2193 clients initially identified as users of day care services, 640 were designated as brief users, 1148 were included in the longitudinal analysis, and 405 were excluded from the analyses either because they continued to use services or their current care status was unknown. Similarly, of the 2690 clients initially identified as users of in-home services, 1432 were included in the longitudinal analysis, 831 were identified as brief users and 427 were excluded from the analyses because they continued to use services or their current care status was unknown.

With only minor exceptions, the characteristics of day care and in-home clients excluded from the longitudinal sample largely mirrored those included in the sample. A detailed comparison of

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characteristics of two longitudinal samples with those of clients excluded from the analyses is provided in Appendix 2E. Generally, for both types of services, Black/African-Americans comprised a slightly larger proportion of the cases excluded from the analysis (i.e. 42% vs. 34% for day care and 40% vs. 30% for in-home). In contrast Hispanic/Latinos comprised a larger proportion of the sample included in the longitudinal analysis for day care respite than in the excluded group (6.7% to 13.1% respectively). In addition, adult children were more prevalent in the longitudinal sample of day care users than in the group excluded from the analysis (52% vs. 46%). Also, for the analysis of in-home respite use, persons from urban locations were less prevalent in the longitudinal sample than in the excluded group (40% vs. 32%).

# Characteristics of Day Care Users and In-Home Users

Demographic data for the 2395 client families who used services for more than two months are reported in Tables 2.9 and 2.10. Characteristics are reported separately for users of day care services and in-home services. Past research has suggested that users of day care services have different profiles than users of in-home services (Montgomery and Kosloski, 2000). This is based, in part, on the belief that the relationship of the caregiver to the care receiver and the magnitude of care required will impact the respite use patterns. In general, adult children comprise a larger portion of day care users, while spouse caregivers are more likely to use inhome respite services. Additionally, spouse caregivers usually wait until much later in the caregiving career to accept services, whereas adult children usually seek formal assistance when help with personal care is needed. Thus, since these user groups are known to be different types of users with different needs at different times, it is important to separate day care users and in-home users from dual service users and to analyze each individually.

## Elder Characteristics

The demographic characteristics of elders, shown in Table 2.9 by service type, are similar to the national profiles of persons with dementia. The majority of the longitudinal sample was White (55.8%), while Black/African-Americans and Hispanics/Latinos made up 32.3% and 8.5% of the sample, respectively. When viewing users of the different services separately, there was a significant relationship between race of the elder and type of service used. In this sample, Whites (63.8%) were more likely to use in-home respite services than were Black/African-American (30.7%) and Hispanic/Latino (3.4%) elders. Hispanics/Latinos elders (15%) made up a somewhat larger proportion of day care users than of in-home users as did Black/African-

TABLE 2.9 ELDER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE

	All Services		•	are Only		me Only	Both Services	
	2395	100%	852	35.6%	1143	47.7%	400	16.7%
*D	N	%	N	<u>%</u>	N	<u> </u>	N	%
*Race	4007	55.00/	004	45.00/	700	00.007	0.17	<b>54.0</b> 0/
White	1337	55.8%	391	45.9%	729	63.8%	217	54.3%
Black/African-American	773	32.3%	293	34.4%	351	30.7%	129	32.3%
Hispanic/Latino	203	8.5%	128	15.0%	39	3.4%	36	9.0%
Other Unknown	67 15	2.8% 0.6%	34 6	3.8% 0.7%	17 7	1.5% 0.6%	16 2	4.0% 0.5%
	15	0.0%	6	0.7%	,	0.6%	2	0.5%
*Geographic Location			.=-	<b>=</b> 0.00/				
Urban	955	39.9%	453	53.2%	351	30.7%	151	37.8%
Rural	1281	53.5%	342	40.1%	712	62.3% 7.0%	227	56.8%
Unknown	159	6.6%	57	6.7%	80	7.0%	22	5.5%
*Average Income								
Under \$5,000	330	13.8%	132	15.5%	149	13.0%	49	12.3%
\$5,000 - \$15,000	1378	57.5%	487	57.2%	650	56.9%	241	60.3%
\$15,001 - \$30,000	402	16.8%	118	13.8%	220	19.2%	64	16.0%
\$30,001 - \$50,000	61	2.5%	21	2.5%	32	2.8%	8	2.0%
Over \$50,000	17	0.7%	7	0.8%	8	0.7%	2	0.5%
Unknown	207	8.6%	87	10.2%	84	7.3%	36	9.0%
Gender								
Male	797	33.3%	289	33.9%	383	33.5%	125	31.3%
Female	1548	64.6%	544	63.8%	738	64.6%	266	66.5%
Unknown	50	2.1%	19.0	2.2%	22	1.9%	9	2.3%
*Marital Status								
Single	124	5.2%	49	5.8%	55	4.8%	20	5.0%
Married	1027	42.9%	305	35.8%	564	49.3%	158	39.5%
Widowed	1096	45.8%	434	50.9%	466	40.8%	196	49.0%
Other	116	4.8%	53	6.2%	46	4.0%	17	4.3%
Unknown	32	1.3%	11	1.3%	12	1.0%	9	2.3%
*Living Arrangement								
Live Alone	342	14.3%	99	11.6%	179	15.7%	64	16.0%
Live with Spouse	1001	41.8%	293	34.4%	556	48.6%	152	38.0%
Live with Children	817	34.1%	350	41.1%	319	27.9%	148	37.0%
Other	214	8.9%	96	11.3%	83	7.3%	35	8.8%
Unknown	21	0.9%	14	1.6%	6	0.5%	1	0.3%
*Total Number in Housel	hold							
Live Alone	342	14.3%	99	11.6%	179	15.7%	64	16.0%
Elder + 1 other	1166	48.7%	350	41.1%	632	55.3%	184	46.0%
Elder + 2 others	459	19.2%	179	21.0%	203	17.8%	77	19.3%
Elder + 3 or more	404	16.9%	208	24.4%	123	10.8%	73	18.3%
Other/Unknown	24	1.0%	16	1.9%	6	0.5%	2	0.5%
Number of Services Use	d Prior to	Entry						
0	822	34.3%	299	35.1%	382	33.4%	141	35.3%
1 - 2	1247	52.1%	437	51.3%	609	53.3%	201	50.3%
3 or more	326	13.6%	116	13.6%	152	13.3%	58	14.5%

<sup>\*</sup> Difference between day care and in-home groups significant at p <= .05

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TABLE 2.9. ELDER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE..continued

All Services		Day C	Day Care Only		In-Home Only		<b>Both Services</b>	
2395	100%	852	35.6%	1143	47.7%	400	16.7%	
Ν	%	N	%	N	%	N	%	
		-				-		
421	17.6%	152	17.8%	203	17.8%	66	16.5%	
1726	72.1%	585	68.7%	848	74.2%	293	73.3%	
242	10.1%	112	13.1%	90	7.9%	40	10.0%	
6	0.3%	3	0.4%	2	0.2%	1	0.3%	
3	3.9		3.0	4	4.7		3.4	
1:	2.7		12.1	1	3.2		12.3	
1:	2.7		12.3	1	2.7	•	13.4	
7	9.3	-	78.3	8	0.0	-	79.7	
	2395 N 421 1726 242 6	2395 100% N % 421 17.6% 1726 72.1% 242 10.1%	2395 100% N	2395         100%         852         35.6%           N         %         N         %           421         17.6%         152         17.8%           1726         72.1%         585         68.7%           242         10.1%         112         13.1%           6         0.3%         3         0.4%           3.9         3.0         12.7         12.1           12.7         12.3         12.3	2395         100%         852         35.6%         1143           N         %         N         %         N           421         17.6%         152         17.8%         203           1726         72.1%         585         68.7%         848           242         10.1%         112         13.1%         90           6         0.3%         3         0.4%         2           3.9         3.0         2           12.7         12.1         1           12.7         12.3         1	2395         100%         852         35.6%         1143         47.7%           N         %         N         %         N         %           421         17.6%         152         17.8%         203         17.8%           1726         72.1%         585         68.7%         848         74.2%           242         10.1%         112         13.1%         90         7.9%           6         0.3%         3         0.4%         2         0.2%           3.9         3.0         4.7           12.7         12.1         13.2           12.7         12.3         12.7	2395         100%         852         35.6%         1143         47.7%         400           N         %         N         %         N         %         N           421         17.6%         152         17.8%         203         17.8%         66           1726         72.1%         585         68.7%         848         74.2%         293           242         10.1%         112         13.1%         90         7.9%         40           6         0.3%         3         0.4%         2         0.2%         1           3.9         3.0         4.7           12.7         12.1         13.2           12.7         12.3         12.7	

TABLE 2.10 CAREGIVER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE

	All Services		Day C	are Only	In-Hon	In-Home Only		Both Services
	2395	100%	852	35.6%	1143	47.7%	400	16.7%
_	N	%	N	%	N	%	N	%
*Gender								
Male	624	26.1%	198	23.2%	322	28.2%	104	26.0%
Female	1703	71.1%	622	73.0%	800	70.0%	281	70.3%
Unknown	68	2.8%	32	3.8%	21	1.8%	15	3.8%
*Relationship to elder								
Spouse	872	36.4%	255	29.9%	481	42.1%	136	34.0%
Adult child / child-in-law	1128	47.1%	447	52.5%	477	41.7%	204	51.0%
Other relative	242	10.1%	80	9.4%	127	11.1%	35	8.8%
Friend	59	2.5%	23	2.7%	24	2.1%	12	3.0%
Professional care manager	45	1.9%	31	3.6%	7	0.6%	7	1.8%
Self	7	0.3%	2	0.2%	3	0.3%	2	0.5%
Unknown	42	1.8%	14	1.6%	24	2.1%	4	1.0%
*Marital Status								
Single/Divorced	504	21.0%	193	22.7%	221	19.3%	90	22.5%
Married	1649	68.9%	566	66.4%	814	71.2%	269	67.3%
Widowed	162	6.8%	54	6.3%	78	6.8%	30	7.5%
Unknown	80	3.3%	39	4.6%	30	2.6%	11	2.8%

<sup>\*</sup> Difference between day care and in-home groups significant at p <= .05 "Difference between both service and single service user groups significant at p <= .05

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<sup>\*</sup> Difference between day care and in-home groups significant at p <= .05

TABLE 2.10 CAREGIVER CHARACTERISTICS BY SERVICE TYPE: LONGITUDINAL SAMPLE --Continued

TABLE 2.10 CAREGIVE							PLECor	ntinued
		rvices		are Only		ne Only		Services
	2395	100%	<b>852</b>	35.6%	1143	47.7% °/	<b>400</b>	16.7%
Age (in years)	N	<u>%</u>	N	<u> </u>	N	<u>%</u>	N	%
44 or less	295	12.3%	117	13.7%	116	10.1%	62	15.5%
45 - 54	383	16.0%	117	16.9%	168	14.7%	71	17.8%
55 - 64	392	16.4%	136	16.9%	179	15.7%	77	19.3%
65 - 74	430	18.0%	132	15.5%	235	20.6%	63	15.8%
75 - 84		16.0%				19.8%		
75 - 64 Over 84	384 75	3.1%	92 14	10.8% 1.6%	226 51	4.5%	66 10	16.5% 2.5%
Unknown	436	18.2%	217	25.5%	168	4.5% 14.7%	51	12.8%
*#Mean age		1.3		8.7		3.6		9.9
_			O	0.7		5.0	O	0.0
*#Education								
Less than high school	507	21.2%	172	20.2%	257	22.5%	78	19.5%
Completed high school	698	29.1%	228	26.8%	364	31.8%	106	26.5%
Vocational training	121	5.1%	44	5.2%	52	4.5%	25	6.3%
Attended college	385	16.1%	159	18.7%	152	13.3%	74	18.5%
College graduate	379	15.8%	159	18.7%	149	13.0%	71	17.8%
Graduate work	89	3.7%	30	3.5%	42	3.7%	17	4.3%
Unknown	216	9.0%	60	7.0%	127	11.1%	29	7.3%
*Employment								
Full-time	654	27.3%	296	34.7%	258	22.6%	100	25.0%
Part-time	212	8.9%	81	9.5%	92	8.0%	39	9.8%
Unemployed	505	21.1%	173	20.3%	228	19.9%	104	26.0%
Retired	829	34.6%	234	27.5%	471	41.2%	124	31.0%
Other	135	9.0%	37	4.3%	72	6.3%	26	6.5%
Unknown	60	2.5%	31	3.6%	22	1.9%	7	1.8%
*Average income								
Under \$5,000	312	13.0%	94	11.0%	159	13.9%	59	14.8%
\$5,000-\$15,000	649	27.1%	199	23.4%	335	29.3%	115	28.8%
\$15,001-\$30,000	544	22.7%	186	21.8%	264	23.1%	94	23.5%
\$30,001-\$50,000	191	8.0%	87	10.2%	74	6.5%	30	7.5%
Over \$50,000	67	2.8%	31	3.6%	23	2.0%	13	3.3%
Unknown	632	26.4%	255	29.9%	288	25.2%	89	22.3%
Driving Distance from E	lder (mir	ns.)						
Lives in same household	1931	80.6%	699	82.0%	903	79.0%	329	82.3%
1 - 10	211	8.8%	71	8.3%	104	9.1%	36	9.0%
11 - 30	133	5.6%	41	4.8%	73	6.4%	19	4.8%
Over 30	28	1.2%	13	1.5%	13	1.1%	2	0.5%
Other/Unknown	92	3.8%	28	3.3%	50	4.4%	14	3.5%
Length of caregiving be	fore pro	gram entry (	(months)					
0 - 6	349	14.6%	129	15.1%	145	12.7%	75	18.8%
7 - 12	258	10.8%	90	10.6%	126	11.0%	42	10.5%
13 - 24	375	15.7%	120	14.1%	180	15.7%	75	18.8%
25 - 36	316	13.2%	115	13.5%	140	12.2%	61	15.3%
37 - 72	490	20.5%	176	20.7%	254	22.2%	60	15.0%
72 or more	387	16.2%	114	13.4%	217	19.0%	56	14.0%
Unknown	220	9.2%	108	12.7%	81	7.1%	31	7.8%
*Mean length of caregivi	41	1.5	3	9.1	4	4.5	3	7.6

<sup>\*</sup> Difference between day care and in-home groups significant at p <= .05 # Difference between both service and single service user groups significant at p <= .05

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American elders (34.4%). In contrast, White elders (45.9%) used day care services in smaller numbers than they did in-home services.

Differences between users of the different types of service in geographic location were also significant. The majority of the total sample was located in rural areas (53.5%) with just under 40% living in urban areas. Approximately 7% of the sample did not specify whether they lived in an urban or rural community. In-home service users were similarly distributed with 62.3% in rural areas and 30.7% in urban centers. In contrast, the majority (53.2%) of the elders using only day care lived in urban areas and just over 40% lived in rural towns.

The majority (71.3%) of all user groups had incomes under \$15,000 per year. This remained true for users of each service type; 73% of day care users and 70% of in-home users had annual incomes under \$15,000. Nearly two-thirds of elders were female. This is consistent with national demographic statistics indicating greater longevity of females, and thus a greater likelihood of requiring assistance with care. A larger proportion of day care clients were widowed (50.9%) and fewer were married (35.8%) than in the sample of in-home respite users (40.8% widowed; 49.3% married).

Living arrangement also varied significantly by service type. The majority of elders either lived with their spouse (41.8%) or their children (34.1%); only 14.3% lived by themselves. A lower proportion of elders using day care resided with a spouse (34.4%) than with an adult child (41.1%). Elders using in-home services were more likely to live with their spouse (48.6%); 27.9% lived with their children, and 15.7% lived alone. Although the largest proportion of elders resided in a two person household with their caregiver, a small proportion lived alone, and 36.1% lived in households of three or more persons. A higher proportion of elders who used inhome services resided in two person households than was true for users of day care (41.1%) or dual users (46%). Conversely a higher proportion of day care users than of in-home respite users (45.4% versus 28.6%) resided in homes with two or more other persons.

Prior to using the demonstration services, just over half the elders in all categories had used one or two other community-based services. The majority of elders (72.1%) had received a

formal diagnosis of Alzheimer's disease prior to enrolling in the demonstration. Fewer elders who used day care (68.7%) had a formal diagnosis than did elders who used in-home respite services (74.2%). This pattern is consistent with the usual timing of in-home respite use within the context of the caregiving career. Caregivers tend to use in-home respite in later stages of the disease process and thus, are more likely to have sought out, or had time to receive, a formal diagnosis. Additionally, 13.1% of elders using day care and 7.9% of elders using in-home respite had a diagnosis other than Alzheimer's disease.

There were also statistically significant differences between the groups in measures of functional status. In-home respite clients had higher average scores on both ADL (4.7) and IADL (13.2) measures than did day care clients, whose scores were 3.0 and 12.1, respectively. Similarly, in-home respite users, on average, had higher scores on the 15-item measure of problem behaviors than did users of day care (12.7 versus 12.3). The lower levels of functioning and greater number of problem behaviors displayed by in-home respite users suggest that clients utilize this service in later stages of dementia. The average age of the elders differed by service type as well, with users of day care being slightly younger (78.3 years) than users of in-home respite (80 years).

## Caregiver Characteristics

Demographic characteristics of caregivers, as shown in Table 2.10, mirrored those of the elders. Females comprised approximately 71.1% of the caregiver population as a whole, with few differences observed between users of day care (73%) and in-home (70%) services. Adult children were the largest segment of caregivers in each group, making up 47.1% of the sample. This percentage varied by service type, with adult children comprising 52.5% of the caregivers who used day care and only 41.7% of those utilizing in-home respite. As expected, the pattern was reversed for spousal caregivers, who made up 42.1% of in-home respite users, and only 29.9% of day care users.

Differences between the two groups in the distribution of marital status and average age are linked to the differences observed in the prevalence of spouse and child caregivers. A higher proportion of the caregivers using in-home services were married (71.2%), as opposed to 66.4% of those involved in day care. With an average age of 58.7 years, caregivers of the day care

group were significantly younger than their peers who used in-home respite (63.6 years). This again reflects the relationship-based differences between users of day care and in-home respite.

Education, employment, and income levels varied for users of the different services. Subtle group differences can be observed in caregivers' levels of educational attainment. In general terms, the educational level of the sample was low, with more than 50.3% having only a high school diploma or less. However, nearly half of day care users had completed vocational training or more schooling (46.1%), while this was true for only 34.5% of caregivers receiving inhome respite. This pattern was also consistent for the caregiver's employment status. The full sample included 654 full-time workers (27.3%) and 829 retirees (34.6%). For in-home respite users, 22.6% of caregivers were working full-time and 41.2% were retired. In contrast, a higher frequency of day care users worked full-time (34.7%) than were retired (27.5%). While 62.8% of the sample as a whole earned less than \$30,000 annually, users of in-home respite are more concentrated at the low end than are day care users. This segment of the income spectrum encompasses 66.3% of persons receiving in-home respite, and 56.2% of those using day care. These disparities likely reflect the differences in age between the caregivers of in-home users and caregivers of day care users. The younger caregivers are generally more likely to provide care while remaining employed, thus resulting in higher household incomes.

Finally, patterns of caregiving are somewhat different between groups. Caregivers' physical proximity to elders was constant throughout the sample; the most common situation was the elder residing in the same household as the caregiver (80.6%). Despite this similarity, caregivers who utilized in-home respite waited longer before seeking assistance from the demonstration. On average, they provided care for 44.5 months before beginning service, while the average for persons who chose day care was 39.1 months.

#### **Characteristics of Users of Both Services**

Primary attention in this report has been given to the distinctive profiles of day care and in-home respite users. By design, each form of respite provides a unique type of relief from caregiving and subsequently attracts different types of clients. However, there are a number of families

who utilize both day care and in-home respite. The longitudinal sample included 400 (16.7%) families who used both types of service. Characteristics of this group (Both Services), shown in Table 2.9 and 2.10, are provided separately from those clients who utilized day care exclusively or in-home exclusively. In identifying users of both services, no minimum amount of either service was required for families to be recorded as dual users of respite. That is, a family could theoretically use only two hours of day care but more than four hundred hours of in-home respite over the course of their participation in this demonstration and still be recorded as a dual user.

Overall, the characteristics of users of both services closely resembled users of day care and inhome clients. However, a small number of significant distinctions were observed. For the elders, these distinctions included differences in the level of ADL, IADL, and problem behavior. For the caregivers, differences were observed in mean age and educational level.

Elders using both services had ADL and IADL scores that were significantly higher (3.4 ADL and 12.3 IADL) than those of day care users (3.0 ADL and 12.1 IADL) and lower in comparison to in-home users (4.7 ADL and 13.2 IADL). This is consistent with findings from past research that indicates a higher disability status for in-home elders than for day care elders. It is not surprising then to find clients who utilize both services having functional levels lower than those of day care users but above users of in-home services. In contrast, problem behavior measures were higher for elders using both services (13.4) than for those using either day care or for in-home (12.3 and 12.7 respectively). This may suggest that families, who must deal with difficult behaviors, seek out additional sources of support.

Caregivers using both services were generally older (59.9 years) than day care users (58.7 years), but younger than in-home users (63.6 years). Again, considering past research indicating that day care is typically used at earlier stages in the caregiving career than in-home services, this finding is consistent with expectations. Additionally, the educational status of caregivers utilizing both services was significantly higher than those using only in-home respite and slightly lower than those who used day care. Forty-seven percent of dual users had attended some form of post secondary education, 17.8% of which had college degrees.

## **Variables and their Measurement**

# Defining and Measuring Respite Use

Although most previous studies have quantified the amount of service use in terms of total hours of respite used, this summary value does not capture the many ways that families may differ in their use of services. Families may vary in (1) the number of hours that is used on each occasion, (2) the duration of time (e.g. number of months) over which a family actually uses services, (3) the continuity of use within that duration period, and (4) the total number of hours of respite that is used. It is not only plausible that families will vary in their patterns of use as conceptualized and measured in these different ways, but it is also likely that a different set of factors may account for the variation in the different measures of use. Therefore, to fully describe patterns of respite use and capture differences among families in their patterns of use, it is important to conceptualize and measure use in several different ways.

For this study, respite use was conceptualized and measured in five ways.

The *intensity* of respite was defined as the number of hours used in each month.

The *duration* of respite use was defined as the number of months between the client's first occasion of use and the last occasion of use.

The *continuity* of respite use was measured as the ratio of number of months in which a family actually used the respite services relative to the number of months for which the family was eligible to use services

The **total hours** of respite used by a client is equal to the sum of all hours used over the eligibility period. (The **eligibility period** was defined as the period between enrollment in the demonstration project and departure from the project for any reason.)

Note that *intensity* of respite use is a time dependent variable that is measured monthly and can be analyzed with longitudinal statistical techniques. In contrast the other three measures of respite use are summary measures intended to capture variations in patterns of respite use that do not lend themselves to longitudinal analyses.

#### Independent Variables

Both client characteristics and provider characteristics were examined as plausible predictors of respite utilization profiles.

Characteristics of Elders and Caregivers. A wide range of characteristics of the elder care recipient and the family member providing care were investigated as possible predictors of respite use patterns. The set of individual characteristics included as plausible predictors was selected based on findings from previous studies of caregiving behaviors and service utilization (see Montgomery and Kosloski, 2000 for a detailed review.) Demographic characteristics of the caregiver included in the analyses are: relationship of the caregiver to the elder (i.e. spouse, child, other family member) ethnicity, gender, income and employment status. The elder characteristics included in the analyses are: gender, age, health and functional status, living arrangement (i.e., alone or with caregiver), and geographic residence (urban versus rural settings).

**Provider Characteristics.** Five types of provider characteristics were considered as factors likely to influence patterns of respite use. They included: (1) caps or limitations on amount of service available to each and a measure of the level of flexibility a provider used in enforcing these caps; (2) hours and/or days of operation; (3) type of staffing (voluntary versus paid); (4) type of service provided (social, companionship, personal care services, or a combination of both levels of care); and (5) fee structure (i.e., set fee, sliding scale, voluntary, or co-pay).

#### **Approach to Statistical Analysis**

A general linear mixed model was used to examine the pattern of client use of the two respite services (adult day care and in-home) over time and to identify the client and provider characteristics that might affect these patterns of use. The mixed model is an appropriate model to use when observations on the dependent variables are nested or clustered such that the assumption of independence of observations is tenuous. In the case of the data analyzed in this study, there is nesting of data both within persons (the monthly repeated measures of the client's service use) and within organizations (the clients nested within service providers). The two levels of nesting in the data make them especially complicated to analyze. We were interested in: (1) determining whether clients' patterns of respite use differ among providers, and (2) identifying client and provider characteristics that might affect patterns of usage. As in any regression analysis, the variance in a model may be explained by a variety of covariates. In the linear mixed model, the between-subjects variance in the level or in the rate may be reduced by the inclusion of selected covariates. In this study, we explored a number of covariates representing characteristics of the elder and caregiver as well as characteristics of providers.

Our analytic approach was to examine these issues for each type of respite service in three steps. First, the patterns of client respite use as captured by each of the four measures (i.e., intensity, continuity, duration, total hours) were examined for each type of service. In the case of intensity, which was measured monthly, these patterns were modeled over time. Second, we examined the effects of client and provider characteristics on each of three summary measures. Finally we modeled the pattern of client use over time as measured by intensity over time and examined together all factors affecting intensity of use. A detailed discussion of the modeling and mathematical foundations for the analysis of the longitudinal data is presented in Appendix 2F.

#### **FINDINGS**

# Average Amount of Respite Use

The mean scores for each measure of respite use are shown by type of service in Table 2.11 along with the average *eligibility period* for clients. For both types of services the average period of eligibility for clients was slightly more than 19 months. The mean *duration* of service use was 14.9 months for families using in-home services and 16.2 months for day care. On average, clients used respite services just over 70% of that period as indicated by the scores for *continuity* of use. In contrast to the similarity of duration observed for the two types of services, there was a significant difference between the two types of services in the average *intensity* (number of hours used) of use by clients. Day care clients used an average of 50 hours of respite per month, which was twice the amount used by in-home clients. This difference in the number of hours used per month was reflected in the large disparity observed between the two types of services in the *total number of hours* used by clients. The average number of total hours of respite used by day care clients was 817 hours as opposed to 283 hours for in-home clients.

Although these general descriptions of the patterns of respite use provide baseline information for policy makers and providers, more valuable information is obtained when differences among caregivers in patterns of respite use are examined carefully. In particular, it is useful to identify client and provider characteristics that are associated with these differences and to examine variations in intensity of use over time.

Even though multi-level analyses were conducted for all of the summary measures of respite use, separate analyses for *total hours* of use are not reported here because the findings related to total number of hours of use are fully captured by the longitudinal analyses of intensity of use.

TABLE 2.11 MEASURES OF USE BY SERVICE TYPE

	Day Care N = 1148			e Respite
	Mean	Std.Dev.	Mean	Std.Dev.
*Period of Eligibility (months)	19.3	13.2	19.1	13.6
Average Intensity (hours of use per month)	50.3	37.1	24.6	17.6
Duration of Use (months)	16.2	12.98	14.9	12.95
Continuity of Use	0.72	0.26	0.71	0.26
Total Hours of Use	817.2	1170.9	282.6	345.5

<sup>\*</sup>Not included as a dependent variable

#### Patterns of Client Use of Day Care

#### **Duration of Day Care Use**

The results of the multi-level analysis for duration of day care use are shown in Table 2.12. These findings reveal several patterns. First, the variance components for random effects reported in the bottom panel of the table indicate that there is some variation among providers in the mean level of client duration. However, the majority [146.22/(146.22+10.63)=93%] of the observed variance in duration of respite use stems from differences among individuals (146.22 versus 10.63).

The data reported in the upper half of Table 2.12 identify the factors that influence duration. Note that all of the factors found to be related to duration of respite use were characteristics of the caregiver or the elder. None of the provider characteristics were shown to be factors influencing the duration of service use. The client characteristics that are related to respite use

**TABLE 2.12 DAY CARE: DURATION OF USE** 

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
Intercept		20.435	1.832	11.15
PERSON VARIABLES				
Race	.0028			
Black/African-Amer.		4.275	1.175	3.64
Hispanic/Latino		356	2.115	17
Other Race		.4189	2.750	.15
White		0		
Employment	.0091			
Full-time		2.417	.818	2.95
Part-time		084	1.244	07
Unemployed		0		
<b>Used Both Services</b>				
Yes	.0001	-3.736	.909	-4.11
No		0		
IADL Score	.0001	497	.116	-4.27
Random Effects		Variance Comp.	z-Value	Prob. Of z
LEVEL ONE				
Individual Variation		146.22	22.84	.0001
LEVEL TWO (Client within Provider Initial Status		10.63	2.36	.0091

are the elder's race and level of IADL impairment, the employment status of the caregiver, and whether or not the family used both types of respite care. The coefficient for the intercept indicates that the average duration of day care use was 20.4 months for persons in the referent group<sup>2</sup>. The average of 20.4 months is obtained by holding constant the effects of all the other predictor variables in the model by fixing their levels at some particular, arbitrary value. In the present case, these arbitrary values are the values for the comparison or omitted groups in the analysis. For this analysis, the intercept represents the average duration for an individual who is White, unemployed, who cares for an elder with no IADL impairment, and who used respite only in the form of day care. The coefficients for the different ethnic groups indicate the increase or decrease in number of hours associated with each group when compared to the referent group. The average duration of respite use for Hispanic/Latino caregivers was only slightly less than that of Whites (-.36 of a month); the duration for persons included in the other ethnic groups was slightly longer (.42 months) than for Whites. The duration of respite use for clients who used both in-home and day care respite was shorter by almost 4 months (-3.7). The

duration of service used decreased by a half of month for every full point increase in IADL impairment. Overall, this analysis indicates that Black/African-American caregivers, who are employed full time and are caring for persons with minimal IADL impairment, tend to use services for the longest periods of time.

# Continuity

Findings related to the continuity of day care use are reported in Table 2.13. Again, the variance components shown in the lower panel of the table indicated that the majority [19.84/(19.84+ 2.24)=89%] of variation in continuity of use was due to variation among individuals, although there was a small, statistically significant amount of variation between providers in the average continuity of service use among clients. Also, as was true for duration, variation in the amount of continuity of use was primarily influenced by individual characteristics rather than provider characteristics. Only the fee structure of the provider had a significant influence on the continuity of service use among clients.

TABLE 2.13 DAY CARE: CONTINUITY OF USE

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
Intercept		.665	.056	11.98
PERSON VARIABLES				
Relationship	.0049			
Child		.037	.019	1.96
Other Relative		039	.027	-1.46
Spouse		0		
Prior Services	.0284			
None		071	.028	-2.60
1 - 2		060	.025	-2.36
3 or more		0		
ADL Score	.0474	007	.003	-1.99
PROVIDER VARIABLES				
Fee Structure	.0083			
Percentage Copay		375	.124	-3.03
Sliding Scale		.036	.050	.73
Voluntary Contribution		.006	.057	.10
Set Fees		0		

Random Effects	Variance Comp.	z-Value	Prob. Of z
LEVEL ONE Individual Variation	.057	19.84	.0001
LEVEL TWO (Client within Provider) Provider Initial Status	.007	2.44	.0074

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The intercept coefficient of .665 indicates that persons with characteristics of the reference category on each predictor variable used day care two thirds of the time for which they were eligible<sup>2</sup>. For this analysis, families in the reference group were those who (1) had a spouse caring for an elder with no ADL impairments, (2) had used three or more services prior to enrollment, (3) used both types of respite after enrollment, and (4) were enrolled in programs with set fees. Coefficients for the covariates in the model indicate that the level of continuity, which could range between 0 and 1, is slightly higher (.037) among families with an adult child caregiver and slightly shorter (-.039) for families with a more distant relative providing care. Families who used no support services or only 1 or 2 support services prior to entering the demonstration used services for a slightly smaller proportion of the eligibility period (-.071 and -.060 respectively). An increase of one point on the ADL impairment score is associated with a .05 increase in continuity. Finally, the requirement of co-payment for use of a program was associated with a large and significant decrease in continuity. In fact, the reduction in continuity of -.375 associated with co-pay would reduce the continuity rate by 50% (.665 -.375).

## Intensity of Day Care Use

Initially, analyses were conducted for three different measures of intensity of services: the average number of hours used per month, the total number of respite hours used over the eligibility period, and the monthly use of respite over the duration of use. Findings for the three different measures were almost identical and therefore only the longitudinal analyses of monthly use are reported here. <sup>3</sup>

Variation in Day Care Use Over time and Across Providers. The use of day care respite by clients over time was analyzed using a three level model, as repeated measures were available on this measure of respite use for each family. As before, all of the potential predictor variables were examined (i.e., client characteristics, caregiver characteristics, provider characteristics, and time). For clarity and parsimony, only the significant predictors are included in the final model. Results of this analysis are shown Table 2.14. The variance components for the random effects shown in the bottom panel reveal several important facts about variation in day care use. The variance component for level 1, which is labeled "temporal variation" indicates that the number of hours of respite used by each client varies significantly over the period that respite is used. The level 2 variance component labeled "client initial status" indicates that there is also significant variation among individuals served by the same provider in the number of hours of day care at the time of initial use. The second variance component

TABLE 2.14 DAY CARE: INTENSITY OF USE

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
Intercept		23.768	7.033	3.38
TIME				
Linear	.8056	.084	.140	.60
Quadratic	.0001	013	.002	-6.58
Linear * Duration	.0004	.016	.005	3.52
Linear * Race	.0022			
Black/African-Amer.		428	.132	-3.25
Hispanic/Latino		147	.191	77
Other Race		.380	.292	1.30
White		0		
PERSON VARIABLES				
Race	.1050			
Black/African-Amer.		3.460	2.832	1.22
Hispanic/Latino		12.761	5.530	2.31
Other Race		5.678	7.373	.77
White		0		
Relationship	.0079			
Child		4.967	1.644	3.02
Other Relationship		4.814	2.266	2.12
Spouse		0		
Used Both Services				
Yes	.0003	6.609	1.835	3.60
No Brior Sorvices	0000	0		
Prior Services	.0636	0.750	0.004	4 47
None 1-2		-2.759 -4.860	2.364 2.182	-1.17 -2.23
3 or more		0	2.102	2.20
Caregiver Gender				
Female	.0017	-5.429	1.672	-3.14
Male		0		
Duration of Use	.0035	.173	.059	2.92
IADL Score	.0383	.468	.226	2.07
PROVIDER VARIABLES				
Day Care	.0366 .0039	-13.483 .012	6.310 .004	-2.14 3.00
Сар	.0039			
Random Effects		Variance Comp.	z-Value	Prob. Of z
LEVEL ONE				
Temporal Variation		275.70	71.61	.0001
LEVEL TWO (Client within	n Provider)			
Client Initial Status		418.46	18.81	.0001
Client Rate of Use		.996	9.73	.0001
LEVEL THREE				
Provider Initial Status	S	356.24	4.61	.0001
Provider Rate of Use		.018	.60	.2758

STUDY TWO \_\_\_\_\_\_ PAGE 115

reported under level 2, which is termed "client rate of use", indicates that there is significant variation between clients in their patterns of increase or decrease in hours of service used over time. The level-3 variance component for "provider initial status" indicates that there is significant variance across providers in the initial level of day care use by clients. The second variance component reported for level 3, which is labeled "provider rate of use", is very small and non-significant. This indicates that the patterns of change in respite use are not significantly different across providers.

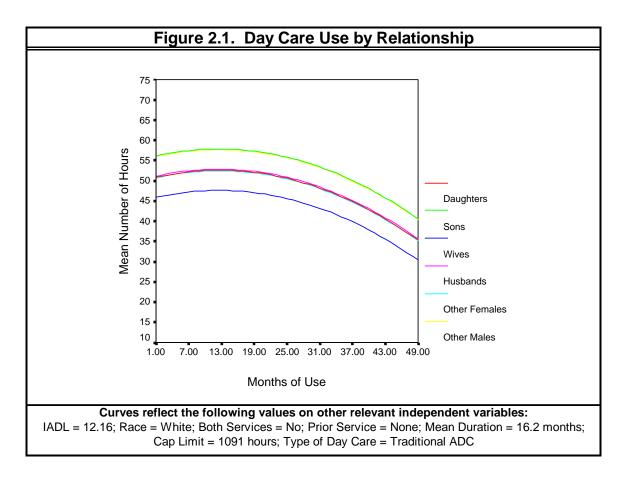
The coefficients reported in the top panel of Table 2.14 provide information about the initial level of day care use, as well as information about the change in this use over time. The linear and quadratic coefficients reported under the heading of "Time" describe the pattern of monthly change in use of day care. As indicated by the non-significance of the linear component, the pattern of change is not linear. The significance of the relatively small negative coefficient (-.013) for the quadratic component indicates that the change in use over time is best described as an "inverted U" which increases slightly to about the tenth month and then decreases more steeply in the later months. This pattern is depicted in Figure 2.1 for six types of caregiver relationships. The findings reported in Table 2.14 also indicate that two client characteristics moderate the pattern of change over time. The coefficients for the multiplicative terms (Linear\*Duration and Linear\*Race) representing the interaction of the linear component with duration and with race are both statistically significant. Since both duration and race also influence the initial level of day care use, it is most helpful to describe the impact of each variable on the trajectory of use with the discussion in the next section of the impact of race and duration on the level of initial use.

Impact of Client Characteristics on Intensity of Day Care Use. The coefficient reported for the intercept term in the top panel of Table 2.14 indicates persons with characteristics representing the reference group on each of the predictor variables will use 23.77 hours of respite in the initial month of respite use. Members of the reference group for this analysis were White, male, spouse caregivers who had used three or more services previously, and were now using only one type of respite service.

Several client characteristics were related to an increase or decrease in this quantity. They

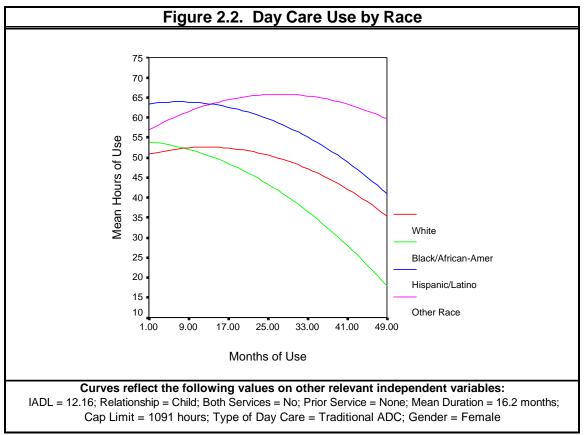
STUDY TWO	PAGE 116
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include: relationship of the caregiver to the elder, race, caregiver sex, elder's level of impairment in IADLs, the number of support services used prior to enrollment in the demonstration, the use of in-home respite and the duration of day care use. Caregivers who were children and other more distant relatives used almost 5 more hours of day care per month than did spouses; female caregivers used 5.4 hours less of day care than did males. Notably there is almost no difference between children and other relatives in the number of hours of day care. The sex of the caregiver also influences the number of day care hours used at the time families begin using services.



The combined effects of these two key caregiver characteristics on the patterns of service use, net of the other factors, are shown in Figure 2.1. The points at which each curve shown in Figure 2.1 intersects the y-axis (Mean Number of Hours) depict this difference in initial level of use. Clearly, the lowest initial use of day care occurs when wives are caring for husbands. It is interesting to note that the level of day care use is almost equal for families with a husband, daughter, or other female caring for the elder. The pattern for sons is most similar to the pattern for "other male relatives".

Referring back to Table 2.14, the average number of hours of respite use in the first month of service was 12.8 hours more for Hispanics/Latinos than for Whites. Although, on average, Blacks/African-Americans used 3.5 more hours of day care than did Whites and persons from other ethnic groups used 5.7 more hours than Whites, differences for these groups were not statistically significant. The differences among racial/ethnic groups in the initial level of day care use did not remain constant over time because race also differentially affected the patterns of change in respite use over time. These differences are illustrated in Figure 2.2. The steeper curve shown for Blacks/African-Americans indicates that the decrease in hours of day care used in later months by Blacks/African-Americans (green line) is much greater than that observed for any of the other ethnic groups. The curve for Hispanics/Latinos (blue line) is only slightly steeper than the curve for Whites, while the curve for caregivers of other ethnic backgrounds is flatter. Thus, over time Black/African-American clients steadily decrease their use, while caregivers of other ethnic groups tend to maintain levels of use consistent with the amount of their initial use.



The differences in level of change over time that are associated with ethnicity lead to interesting changes in the relative ranking among ethnic groups in intensity of use. As shown in Figure 2.2, White families used the lowest number of hours of respite when they initially began using day

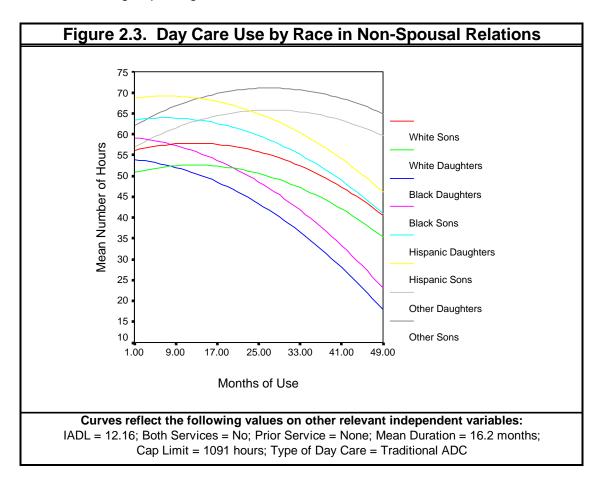
STUDY TWO \_\_\_\_\_\_ PAGE 118

care; Hispanic/Latino caregivers used the highest number of hours at the time of initial use. Additionally, the number of hours of day care used initially by Black/African-American families and families from other backgrounds ranged between Whites and Hispanics/Latinos. Over time, this pattern changes. The number of hours of day care use by Black/African-American families drops below the level for Whites at about the 10-month point. By the end of 49-month period shown in Figure 2.2, the intensity of respite use among Black/African-American families is substantially lower than that of all of the other groups. In contrast, after about 16 months of use, caregivers designated as "other ethnic groups" have higher levels of services use than all other groups. They tend to maintain this higher level through their duration of use. The patterns of change for Hispanics/Latinos and Whites are very similar, resulting in greater intensity of day care use for Hispanics/Latinos throughout the 49 months charted in the graph.

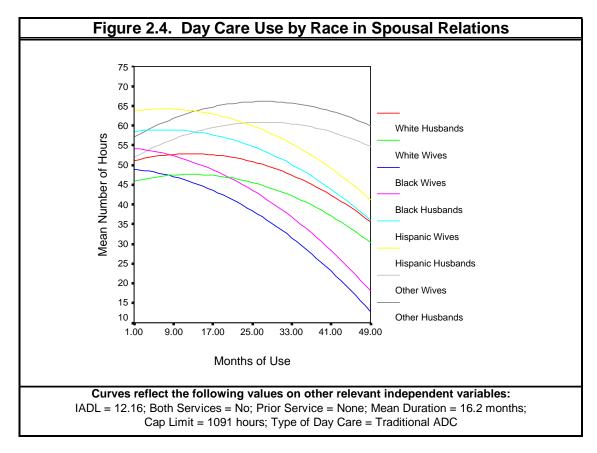
The combined impact of type of caregiver relationship, gender and race are illustrated in Figures 2.3, 2.4, and 2.5. Several differences in the patterns of use for the different groups are worthy of note. First, the curves depicted in Figure 2.3 for sons and daughters indicate the relative influence of race and gender on patterns of care changes over time. At the time of initial service use, Hispanic caregivers use more day care than do caregivers from any of the other ethnic groups regardless of their gender. In contrast the gender of the caregiver is more important than race for Black/African-American and White caregivers. Both Black/African-American and White elders who are cared for by a son use more services at the time of initial day care use. This pattern changes over time with race becoming more important for predicting service use among long term users (at about 20 months) than is gender. Also, the trajectory of change for elders from the category "other ethnic groups" increases for a longer period of time than is true for any of the other groups. Consequently, the number of hours of day care used by elders in this group surpasses that of Hispanics after approximately 25 months of use. Among all racial groups, elders cared for by sons use more services than do those assisted by a daughter.

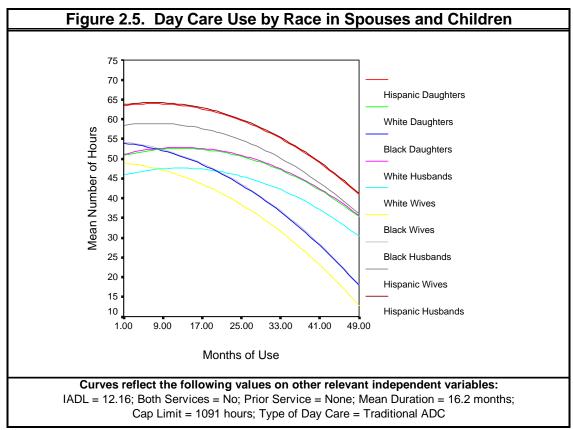
A similar pattern of differences in day care use is depicted in Figure 2.4 for husbands and wives. At the point of initial use, Hispanic elders used more hours of care than did any of the other ethnic group regardless of the gender of the spouse caregiver. For the other three ethnic groups, the influence of race and gender are more equal. While wives in each ethnic group used fewer services than did husbands of the same ethnic group, wives in the "other ethnicity" group used more services than either Black/African-American or White husbands. Among long

term users of day care, race dominates over gender as a predictor of service use. After approximately 25 months of service use, there is a clear ranking of service use by race with husbands in each group using more than wives.



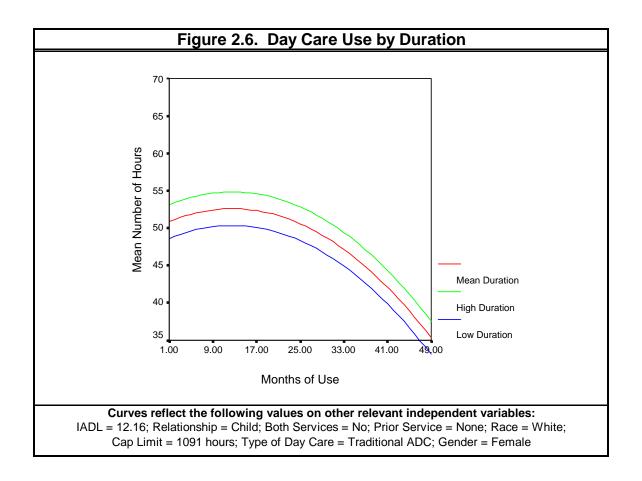
The curves depicted in Figure 2.5 are particularly interesting because they illustrate the similarity among elders cared for by husbands and daughters. For every ethnic group, husbands and daughters used more services than did wives and their patterns of use over time continued to be almost identical. Throughout the entire duration of use, Hispanic/Latino elders used more day care than any other group. The pattern for Whites and Blacks/African-Americans is slightly different. At the time of initial use Blacks/African-Americans of all relationships use more hours of service than do Whites. Over time this pattern is reversed. After 9 months of service use, Black/African-American elders used fewer hours of day care than did their White counterparts with similar role relationships (i.e. husband, wife, daughter). After 19 months of service use, Black/African-American elders used fewer hours of service than all of the other ethnic groups regardless of the caregivers' relationship to the elder.





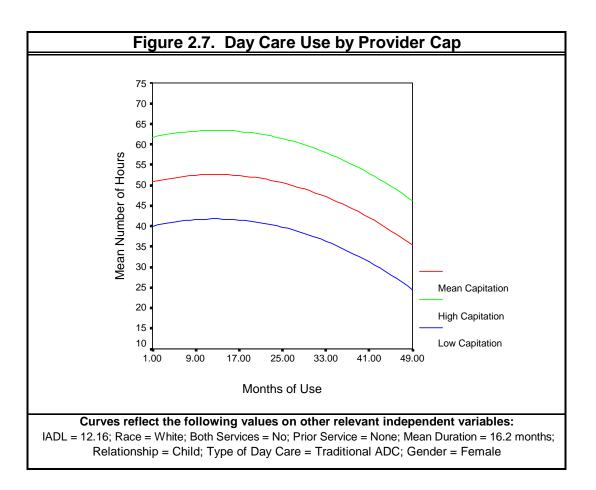
The data reported in Table 2.14 detail the impact of four additional client characteristics on the initial level of service use. For each point of increase in the measure of IADL impairment the number of hours of day care used increased by about one half-hour per month. Clients who used only day care services used 6.6 more hours of service (6.61) than did clients who used both types of respite care. Clients who had previously used no support services used 2.8 hours less of day care (-2.75) than those who had used three or more services prior to enrolling in the demonstration. Persons who had used one or two support services prior to enrollment in the program used almost five fewer hours of day care (-4.9).

Finally, in Table 2.14, the number of hours of day care used in the first month was greater by 0.17 for each additional month that a family ultimately used day care. Duration is the only characteristic, other than race, that changes the shape of the curve. However, the impact of duration on the rate of use was very minimal as shown in Figure 2.6. Essentially the amount of



day care use remained constant over the first 12 months. After that point, however, there was a tendency for all families to use similar amounts of service regardless of the duration of their use. That is, persons who ultimately went on to use services for a full 49 months (green line) tended to reduce the number of hours they used by a greater amount than did those families who used services for shorter periods. As a consequence, the curves depicting levels of use converge over time.

Impact of Provider Characteristics on Intensity of Use Two characteristics of the providers were associated with the intensity of day care use. Families who used group day care used 13.5 fewer hours at the time of initial use than did families enrolled in traditional day care programs. Also, the number of hours of day care used increased by .012 for each hour that was added to the maximum limit or cap that was placed on services by the provider. This difference related to agency caps is depicted in Figure 2.7. The center line in red represents the pattern



for families served by providers who have a limitation of 455 hours which is the mean level among the providers. This mean value represents the mathematical average of all provider caps. The other two lines represent the levels that are one standard deviation above and one standard deviation below this mean level. This range, represented by the standard deviation, captures the use patterns of 68% of the sample.

# Patterns of In-home Respite Use

#### **Duration of In-home Use**

The findings from the multi-level analysis of duration of in-home service use are reported in Table 2.15. The variance components for random effects reported in the bottom panels reveal a pattern similar to that observed for duration of day care use. Ninety-two percent of the variance (150.1/(150.1+13.6)) in the duration of in-home use stems from differences among individuals (where the variance component for individuals = 150.10 versus 13.56 for providers).

TABLE 2.15 IN-HOME RESPITE: DURATION OF USE

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
Intercept		19.639	1.626	12.08
PERSON VARIABLES Race	.0107			
Black/African-Amer. Hispanic/Latino Other Race		3.017 4.139 490	.987 2.374 3.002	3.06 1.74 16
White		0		
Used Both Services Yes No	.0001	-3.757 0	.896	-4.19
Elder's Age	.0001	177	.042	-4.19

Random Effects	Variance Comp.	z-Value	Prob. Of z
LEVEL ONE Individual Variation	150.10	25.97	.0001
LEVEL TWO (Client within Provider) Provider Initial Status	13.557	4.805	.0024

The data reported in the top panel of Table 2.15 identify the factors that influence duration. Consistent with the findings for day care use, all of the factors found to be related to duration of in-home respite use were characteristics of the caregiver or the elder. None of the provider characteristics were shown to be factors influencing the duration of service use. The client characteristics that are related to in-home respite use are the elder's race and age and whether or not the family used both types of respite care. The coefficient for the intercept indicates that the average duration of day care use was 19.6 months for members of the referent group who are families with a White elder, aged 51 years who was using only in-home respite. The average duration of in-home respite use for Hispanic caregivers was 4.1 months longer. On average, Black/African—American elders used in-home services for 3 months longer than did Whites. Caregivers of other ethnic backgrounds did not vary significantly from Whites in the duration of use. The use of day care in combination with in-home respite reduced the average duration of in-home services by 3.8 months (-3.75). The use of in-home services was higher by about 5 days (.17 of a month) for each additional year of the elder's age.

# Continuity of In-home Use

The findings related to continuity of in-home respite use over the period of eligibility are reported in Table 2.16. The variance components in the lower panel of the table indicate that variation in continuity occurs between individuals and across providers. As was true for duration, characteristics of the providers were not associated with continuity. In fact, continuity was found to be related to only two of the many variables investigated (geographic residence of the elder and the level of impairment of ADL). The intercept coefficient indicates that the continuity of inhome respite use was .66 for elders with no ADL impairment and who resided in urban settings. Elders residing in rural areas used in-home respite more continuously over the time that they were eligible for services than did elders in urban areas. The continuity score for elders residing in large cities was .07 lower than for those in a rural setting and the ratio for elders in small cities (population between 2,500 and 50,000) was .02 less than that of elders in rural settings. In contrast, the continuity ratio was .03 higher for elders residing in small towns (population less than 2500 population) than for those in rural settings. Continuity increased by a small amount (+. 005) for each point increase in the level of ADL impairment.

3.30

.0005

TABLE 2.16 IN-HOME RESPITE: CONTINUITY OF USE

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
Intercept		.662	.028	24.00
PERSON VARIABLES				
Geographic Location	.0103			
City or Suburb (> 50,	000)	072	.030	-2.42
Smaller than city but	> 2,500	017	.022	073
Town < 2,500		.031	.024	1.30
Rural Setting		0		
ADL Score	.0234	.005	.002	2.27
Random Effects		V <u>ariance Com</u> p.	z-Value	Prob. Of z
LEVEL ONE Individual Variation		.056	23.45	.0001

# Intensity of In-home Use

LEVEL TWO (Client within Provider)

Provider Initial Status

Variation Use Over time and Across Providers. Results of the longitudinal analysis of inhome use are shown Table 2.17. The variance components for the random effects shown in the bottom panel reveal patterns that reflect significant variation in all components. The variance component for level 1, which is labeled "temporal variation" indicates that the number of hours of in-home services used by each client varies over the duration of use. The level 2 variance component labeled "client initial status" indicates that there is significant variation in the number of hours of respite at the time of initial use among individuals served by the same provider. The second variance component reported under level 2, which is termed "client rate of use", indicates that there is also significant variation across clients in their patterns of increase or decrease in hours of service used over time. The level 3 variance component for "provider initial status" indicates that there is significant variance across providers in the average number of hours used by their clients. The second variance component reported for level 3, which is labeled "provider rate of use", is small but statistically significant. This indicates that the patterns of change in in-home respite use also differ significantly across providers.

.013

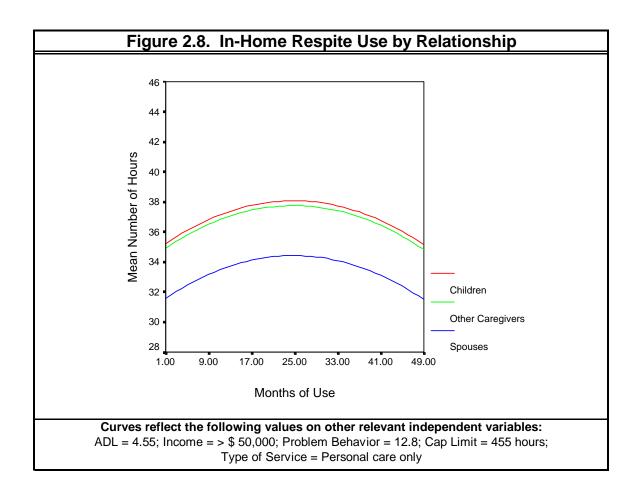
TABLE 2.17 IN-HOME RESPITE: INTENSITY OF USE

Fixed Effects	Effect Prob.	Coefficient	Stnd. Error	t Ratio
I IACU LIICUIS	Lifect 1 10b.	Coemicient		- t italio
Intercept		11.271	3.820	2.95
TIME				
Linear	.0140	.248	.101	2.46
Quadratic	.0023	005	.0015	-3.05
PERSON VARIABLES				
Relationship	.0021			
Child		3.649	1.073	3.40
Other Relationship		3.330	1.555	2.14
Spouse		0		
Income Group	.0034			
Under \$5,000		-2.862	3.578	80
\$5,000 - \$15,000		-1.895	3.402	56
\$15,001 - \$30,000		581	3.455	17
\$30,001 - \$50,000		5.613	3.749	1.50
Over \$50,000		0		
ADL Score	.0092	.425	.1630	2.61
Problem Behavior	.0002	.251	.068	3.72
PROVIDER VARIABLES				
Сар	.0001	.017	.003	5.62
Type of Service	.0094			
Social/Companionshi	р	4.408	2.653	1.66
Personal Care Only		10.001	3.314	3.02
Both Companionship an	nd Personal Care	e 0		
Random Effects		Variance Comp.	z-Value	Prob. Of z
LEVEL ONE				
Temporal Variation		180.95	67.21	.0001
LEVEL TWO (Officers 1911)	- Duardal\			
LEVEL TWO (Client within Client Initial Status	n Provider)	220.24	40.47	0004
Client Initial Status  Client Rate of Use		226.31 .887	19.17 8.30	.0001
Chent Rate of USE		.001	0.30	.0001
LEVEL THREE				
Provider Initial Status	s	21.910	2.40	.008
Provider Rate of Use		.162	1.86	.031

The coefficients reported in the top panel of Table 2.17 provide information about the intensity of in-home service use at the onset and the change of intensity over the duration of use. The coefficients for the linear and quadratic components are both statistically significant, indicating a

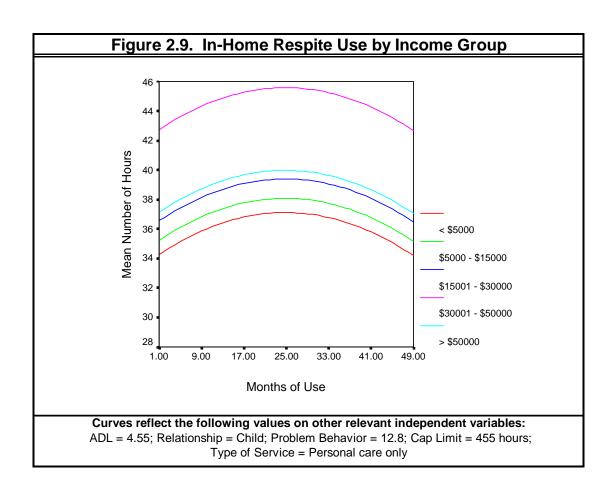
STUDY TWO \_\_\_\_\_\_ PAGE 127

pattern of change in respite use that can be described as a shallow inverted U-shaped curve. This curve was found to be consistent across all segments of the sample and is shown in Figure 2.8 for the three types of caregiver relationships. All differences in the level of in-home service use observed across segments of the sample were associated with differences in the initial level of service use.



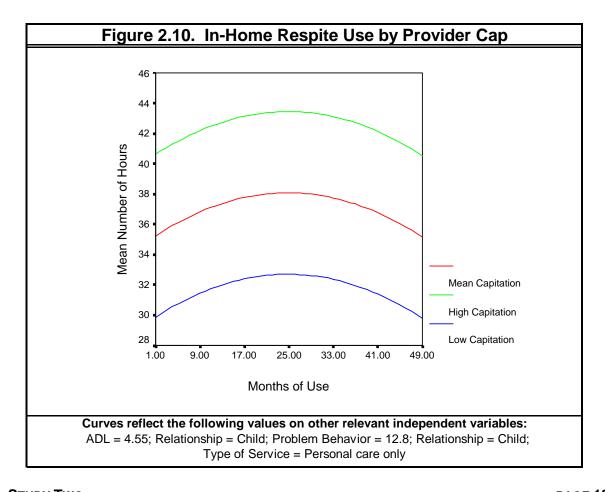
The coefficient reported for the intercept (referent group) indicates that an elderly client will use 11.27 hours of in-home respite service if he or she is: (1) cared for by a spouse, (2) has an income over \$50,000, (3) has no impairment in ADL, (4) exhibits no problem behaviors, and is being served by a program that (5) provides both social and health services. For this analysis, the service cap was centered at 50 hours of use per year, which is the lowest cap set by a provider in this sample. Elders cared for by an adult child used 3.6 hours more per month and those cared for by a more distant relative will use 3.3 hours more service.

As depicted in Figure 2.9, the number of hours of in-home service used by clients is also related to client income. This relationship, however, is not linear. The group that used the highest number of hours of in-home services was in the middle-income group that earned between \$30,000 and \$50,000 dollars. This group used an average of 5.6 hours more service than did the high-income group (over \$50,000 per year). The other three groups, which include the lowest income groups, did not differ significantly from the high-income group. This curvilinear pattern is of special interest because it is the opposite of the pattern that has been frequently observed for nursing home placement. In contrast to the pattern of greater use of in-home services observed for middle-income clients in this study, studies of nursing home placement report less use of nursing home care by this group and higher use of nursing homes by both the low-income and high-income groups. In combination, these patterns suggest that middle-income clients do, indeed, use respite care as a mechanism for avoiding nursing home placement.



Increased impairment in ADL and higher prevalence of problem behaviors are both associated with more intense use of services. The numbers of hours of in-home service used by clients increased by .43 for each point increase in ADL and by .25 hours for each point increase in the problem behavior measure (Table 2.17).

On average, clients served by agencies providing only personal care services used ten more hours of in-home care per month than did persons who received care from an agency offering both companion care and personal care services. It is also the case that clients served by programs that offer only social or companion services used 4.4 more hours of service than did those who were served by agencies offering both personal care services and companion care. Finally, as was true for day care, the limitation or cap placed on service availability by the provider was associated with the number of hours clients used services. For each additional hour allowed by the provider, the average monthly service use by clients was .017 of an hour higher, as shown in Table 2.17 and illustrated in Figure 2.10.



STUDY TWO \_\_\_\_\_\_ PAGE 130

#### DISCUSSION

Several general trends can be identified from the findings detailed in this study. Most importantly, the analyses underscore the fact that characteristics of the elder, the caregiver, and provider are all associated with patterns of respite use. However, the influence of each of these sets of characteristics varies depending upon the definition of use and which measure of respite use is examined.

# **Brief Use**

The decision of a caregiver to continue or discontinue use of services after an initial trial period appears to be most related to the characteristics of the service provider. The analyses that identify characteristics of brief users suggest that caregivers make judgements about the appropriateness or usefulness of a respite program for their caregiving situation and then act in accord with this judgement. The provider characteristics identified as predictors of continued day care use provide an interesting picture. The positive correlation between problem behavior and brief user status indicates that the day care programs do not accommodate elders who frequently engage in problem behaviors and therefore these elders quickly discontinue using day care. In contrast, the longer periods of respite offered by day care programs as opposed to in-home programs are useful for caregivers who are employed full time. Employed caregivers can use day care as a long term care option that enables them meet their work obligations while simultaneously retaining primary responsibility for the care of the elder. This conclusion is supported by the fact that the level of service capitation is negatively related to brief use. Programs offering longer hours of care enable working caregivers to continue using day care services. Finally, the higher concentration of minority caregivers who continue to use day care suggests that the providers offering these services as part of the ADDGS project were successful in conveying their openness and accessibility to these diverse groups.

When considered together, the factors that predicted brief use of in-home services reflect the preference of caregivers who initially seek in-home services for higher levels of care that are best offered by well-trained professionals. Users of in-home respite tend to discontinue use of programs that are staffed by volunteers and do not provide assistance with personal care tasks.

## Sustained Use

In contrast to the provider characteristics that predict brief use, client characteristics are the primary predictors of the duration of respite use and the continuity of service use once the decision has been made to continue using services. Both ethnicity and the client's use of both types of respite services are associated with duration of use. As a group, Black/African-Americans use day care for a longer period time than any other group. They also use in-home services for a period similar to that of Hispanics/Latinos and longer than either Whites or persons from other ethnic groups. This pattern suggests minority groups will use services and will continue to use services once they judge the service to be appropriate for their needs. The fact that clients who use both in-home and day care services tend to use each service for shorter periods of time, suggests that clients who have the option of using multiple services shift from using day care to using in-home care when there are significant changes in the elder's level of functioning or their caregiving context. That is, when clients have a choice of types of respite care, they are better able to match services to their needs throughout their caregiving career. This interpretation is supported by the additional finding that level of IADL impairment is negatively related to duration of day care use. To summarize, as long as elders are able to function in a day care setting, they continue to use that service. When elder impairment becomes too high, families are likely to seek in-home services.

The changing needs of individuals are also linked to patterns of *continuity* of service use. Of note is the fact that the level of ADL impairment is *positively* related to continuity of in-home service use but *negatively* related to the continuity of day care use. Clearly, persons with high levels of ADL impairment are not well served by day care programs, but high ADL impairment scores indicate a need for regular in-home care. The fee structure is the only provider variable that is related to continuity of use of day care services. When families are required to pay part of the costs of care they tend to use services less frequently.

Together these diverse findings about predictors of brief user status, *duration* of respite use and continuity of respite use underscore the differences in the kind of support that is afforded by each type of respite. Day care is most often used as a support system when caregivers must be away from the home or when caregivers have other obligations that require their attention. In this capacity, day care allows caregivers to retain responsibility for the care of the impaired elder

while meeting other work and family obligations. However, when the impairment level of the elder increases to higher levels, caregivers must make an important lifestyle decision. For adult children who cannot leave a parent at home alone, that decision may well be to cease caregiving. Clearly, a greater number of spouses continue to provide care when day care is no longer appropriate for their level of need. Consequently, spouses are more frequent users of inhome respite care.

Both client and provider characteristics are related to the number hours of respite used on each occasion and to changes in the intensity of use over time. The influences of four types of caregiver characteristics are particularly informative. First, the client characteristic most consistently related to the quantity of respite use is the caregiver's relationship to the elder. In general, elders who are cared for by spouses use significantly fewer hours of respite care than do their peers who are cared for by an adult children or other more distant relatives. The number of hours of day care used also varies significantly with the gender of the caregiver. Elders with male caregivers use more respite services.

The functional level of the elder is also clearly related to the amount of respite used. Among users of in-home respite, higher levels of ADL impairment and problem behaviors are associated with greater use of services. Because elders using day care tend to have low ADL impairment, day care use is most related to level of impairment in IADL. Although high levels of IADL are associated with a shorter duration of day care use, high levels of IADL are also associated with greater continuity of use and more hours of use on each occasion. Moreover the number of hours of use during a month increases with duration. This pattern of associations further underscores the fact that day care programs serve a different segment of the caregiving population than do in-home respite programs.

Ethnicity is also an important predictor of levels of respite use and this association between ethnicity and use is a complex issue. Different ethnic groups have distinct trajectories of service use over time. Although Black/African-American elders use day care for a longer duration period than does any other group, the amount of day care used each month diminishes over time to a point that they become the group with the lowest level of use after an extended period of use. In contrast, as a group, Hispanic/Latino elders use day care for the shortest duration

period, but their level of use is the highest of any ethnic group at the time of initial use. Also, they maintain this higher level of use relative to Whites and Blacks/African-Americans throughout the duration of their use. Clearly, the pattern of day care use for Hispanics/Latinos is distinct from that of both Whites and Blacks/African-Americans, but the two groups do not differ in the total number of hours of day care use. Blacks/African-Americans tend to use smaller quantities over a more extended period of time, while Hispanic/Latino elders use high quantities for short periods.

Finally, income is a significant predictor of use of in-home services. The highest level of in-home service use is observed for middle-income elders who tend to have little discretionary money but who are not eligible for Medicaid. This is the group that is least likely to place an elder in the nursing home. Consequently, it is not surprising that they are the highest users of in-home respite. For them, in-home respite is probably the most economical solution for long term care.

Two provider characteristics influence service use for both types of respite services. As would be expected, the amount of service for which a client is eligible clearly influences the level of service use. In addition the level of care that a program provides is related to the amount of respite use. The higher level of service among clients of programs that offer health related or personal care services is consistent with the notion that families seek more intense services when elders have higher levels of need.

The association observed between level of service capitation and the level of use deserves serious attention. This connection suggests that providers that cap services may not be effectively distributing their resources among clients with different levels of need. If services were being used in accord with client need, the level of individual use should not be related to provider caps.

## **Practice Implications**

The findings from these analyses are very extensive and can be used by policy makers and providers to guide the development and delivery of support services. A small number of

implications are identified here for consideration.

First, the findings underscore the importance of using multiple definitions of use when creating profiles of respite use for different segments of the target population. Accurate estimates of the cost of respite cannot be made without clear knowledge of the duration, continuity, and amount of respite use over time.

Second, when planning and budgeting for respite services, providers would be wise to pay close attention to the characteristics of their client pool. Clearly, there are differences in the type of services used and the patterns of service use that are associated with the relationship of the caregiver to the elder, the ethnicity of the caregiver, and the functional levels of the elder. All of these factors will influence the type and quantity of services that should be made available and ultimately, the costs of these services. Moreover, differences among these segments of the target population create an imperative for offering multiple forms of respite to meet their different needs and to continue to provide support as the needs of individual families change over time. This analysis provides solid evidence that in-home respite programs serve a very different population than do day care programs.

Finally, the findings from this study should prompt providers to consider carefully the levels of care they provide and any limitations on the amount of services that are provided to a client. When providers offer only the lowest levels of care, many families will be unable to use respite services. Similarly, when providers cap the level of service use for all clients, they may not be distributing their resources in the most effective manner. Limitations placed by providers on the level of care offered, and the amount services made available to clients, are likely to create significant barriers to appropriate use of services. Many clients will go unserved, others will be underserved, and still others may receive an excess of service. The effective targeting of resources will require close scrutiny of characteristics of the target population and development of multiple levels of respite care.

## **ENDNOTES**

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<sup>&</sup>lt;sup>1</sup> Initially, a model including two dichotomous variables representing the type of day care program (i.e. ADC only, Group Day only, or Both types of day care) was tested. However, the findings from that model did not differ significantly from the more parsimonious model depicted in Table 2.7 which was parallel to the model used to predict brief use of in-home services.

<sup>&</sup>lt;sup>2</sup> This analysis proceeds by "centering" the data on a **referent profile** and calculating the variation for other profile components from that referent profile. That is, for Table 2.12, the data is centered on White unemployed caregivers who care for an elder with no IADL impairment and who only used day care. The referent profile can be identified by the zeros in the coefficient column. (0 represents that there is no variance from the referent profile—they are one in the same.) Thus, the **coefficient** for the **intercept** at the top of the table, 20.435 represents the average number of hours of day care use by the referent profile. To identify the average hours for other profiles, one adds or subtracts the appropriate coefficients. For example, a Black/African-American (coefficient 4.275) who is employed full-time (coefficient 2.417) who used both respite services (coefficient -3.736) would have an average use profile of 23.391 hours [20.435 (referent profile) + 4.275 (Black/African-American coefficient) + 2.417 (employed full-time coefficient) – 3.736 (used both respite services coefficient) = 23.391 hours.

<sup>&</sup>lt;sup>3</sup> Findings for these analyses are available upon request.